

Human-rights-based Support, Empowering Families and Informal Carers of Persons with Disabilities



► Table of Contents

4 Acknowledgements

5 Summary

7 Abstract

8 State of Play

10 Aim of the Study

11 Methodology

13 Findings

41 Conclusions

43 Summary and recommendations

46 Annex 1: Methodology

51 Annex 2: Examples of Promising Practices



► Acknowledgements

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Jan Šiška and Julie Beadle-Brown have dedicated a substantial part of their careers so far to engaging in higher education, research, and consultation with various stakeholders. Their wide-ranging expertise is framed by disability policy and practice at national, European, and global levels. They have been serving for almost three decades as consultants, researchers, external project evaluators, and trainers for various European and Global projects relevant to disability support services and families, with technical expertise in a range of different research and evaluation methodologies and dissemination methods. Their recent projects, thematically relevant to this conference, were the Innovative Frameworks for Measuring the Quality of Services for Persons with Disabilities (2021), and the Study on Service Providers' Implementation of Quality Approaches (2024), both by EASPD. In these projects, they developed approaches based on human rights (UNCRPD) and the eight Quality of Life domains to give services and other stakeholders, including families and other informal carers, a vision of what they should be working towards, helping people achieve. Jan and Julie have led several national and European research projects demonstrating their experience in project management, data collection, analysis, and presentation. Jan and Julie are co-authors of a recent book on the quality of social services for people with disabilities, "The Development, Conceptualisation and Implementation of Quality in Disability Support Services." In addition to other substantial publications in academic journals and books, many of their publications have been written (in whole or in part) in a range of formats for different audiences, including in easy-to-read design language.

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► Summary

Informal carers—family members, partners, friends, and neighbours who provide unpaid care—are the backbone of long-term support for children and adults with disabilities and other long-term conditions across Europe. Over 80 % of long-term care is provided informally, often without training or financial recognition. This burden falls disproportionately on women, who make up the vast majority of informal carers, frequently at the cost of their own employment, income, and well-being. As Europe’s population ages and family networks shrink, this reliance is becoming unsustainable, underlining the need to promote gender equality and better support all carers.

This small-scale European study explores not only the challenges informal carers face but also the approaches, technologies, and policies that families have found helpful—or believe would have been helpful—in supporting children and adults with disabilities to live full, included lives in the community. Evidence was gathered through a literature review, focus groups with informal carers and service providers and stakeholder review of emerging promising practices.

Key findings

✓ Heavy and complex responsibilities

Carers experience stress, exhaustion, financial insecurity, and social isolation. The “sandwich generation” of women aged 35–64 is particularly affected. Employment and pension rights remain limited, and mental health risks are significantly higher than in the general population.

✓ Systemic barriers and gaps

Families often lack timely information and must coordinate services themselves, encountering fragmented systems and inconsistent support. There is limited whole-life, person-centred planning, and limited access to affordable housing, respite, and inclusive education or employment opportunities.

✓ Uneven recognition and support

Legal and financial frameworks vary widely between EU Member States. While some countries provide care allowances, personal budgets, respite services, or navigation support, others offer minimal assistance. Even where progressive policies exist, implementation is inconsistent and rarely monitored.

✓ Promising practices exist

Despite resource constraints, families and service providers shared many examples of successful practice, including early coordinated support services, independent navigation, peer and sibling support groups, personalised funding models, inclusive sports and arts programmes, creative housing solutions, and progressive employment initiatives. These illustrate what can be achieved when communities, non-government organisations (NGOs), and public agencies collaborate. The study demonstrates that change is possible now. Good practice can begin at the local level—even a single organisation or small collaboration can drive meaningful improvements.

Recommendations

Government/policymakers (local, national, EU)

- ✓ Clarify in law and policy that the complexity of a person's support needs can never be grounds for institutional or residential placement, and that all individuals are entitled to person-centred, community-based living arrangements. With the right support, everyone can and should, as a matter of right, live in a home of their own, chosen from the same living options available to people without disabilities at a similar age and stage of life.
- ✓ Make deinstitutionalisation a mainstream activity, not a project and the development of community-based support a priority. Back it up with long-term, protected funding. Enforce legislation and monitor outcomes to ensure UNCRPD is progressively realised.
- ✓ Shift resources from institutional care to personalised, community-based options, with funding that follows individual needs.
- ✓ Improve EU-wide data collection, setting clear definitions to be used and a minimum dataset to be returned, monitor quality of life outcomes, and collect data on implementation and quality of life outcomes of people over time, with a particular focus on innovative solutions to housing and support challenges.

Service planners & public authorities

- ✓ Introduce person-centred, all-age, whole-life planning to ensure smooth life transitions for individuals and their families, and to inform local service development at a system level.
- ✓ Ensure that schools, health care, and leisure services are locally available, accessible, and inclusive.
- ✓ Establish a single, regularly updated information hub, and expand independent navigation and advocacy services.
- ✓ Develop mechanisms to include the voices of people with disabilities and their families, and to ensure multi-agency and cross-sector collaboration.

Service providers & employers

- ✓ Provide early training for families, peer support groups, and gender- and culture-sensitive respite, leisure and social opportunities.
- ✓ Look for opportunities and innovative ways to expand the existing offer of services – find ways to offer personal assistance and bespoke support, even just to a few people with higher support needs. Document how you did it and evaluate the experiences and outcomes. Share with other providers.
- ✓ Ensure carers can reconcile work and family life with adequate leave, flexible employment, and pension protections.
- ✓ Improve pay, conditions, and training for support workers and other professionals to secure a skilled, stable workforce.
- ✓ Encourage joint ventures and resource sharing among providers and promote private-sector social responsibility to strengthen local capacity.

Disabled people's organisations, family support organisations and advocacy groups

- ✓ Work collaboratively with each other – be “stronger together” in advocacy.
- ✓ Work collaboratively with stakeholders at all levels to ensure that the voices of people with disabilities and their families are consistently heard in decisions about services.
- ✓ Create opportunities to share positive experiences and lessons learnt from new initiatives so that development can continue over time.
- ✓ Look for ways to expand independent navigation, advice and advocacy services (shared with planners/government above).
- ✓ Encourage and support person-centred, whole-life planning that focuses on individuals—their hopes, dreams, and aspirations—rather than solely on the services they need.

► Abstract

Informal carers—family members, partners, friends and neighbours who provide unpaid care—deliver over 80 % of long-term support for children and adults with disabilities across Europe. Yet they often face stress, financial insecurity, and limited access to information, respite, and person-centred planning. This study combined a literature review with stakeholder consultations and focus groups in several European countries to examine both the challenges faced by informal carers and the supports that help them. The research identifies ten areas of promising practice, including early

coordinated support, independent navigation, peer and sibling support, personalised funding, inclusive education and employment initiatives, and creative housing solutions. While progressive policies exist, their implementation and monitoring remain inconsistent. The report concludes that stronger political will, long-term investment, and funding that follows the person are essential to scale up these approaches. Empowering families and expanding community-based services are key to realising the UN Convention on the Rights of Persons with Disabilities.



► State of Play

Informal care plays a central role in supporting people with chronic illness, disability, or long-term care needs across Europe. Eurocares defines an informal carer as “a person who provides – usually – unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.”¹ Informal care is contrasted with formal care, which is delivered by paid professionals or administratively and legally established entities. Informal care is embedded in family and social relationships. Informal care is not just a technical act of care, but a practice influenced by emotional bonds, cultural expectations, and moral obligations. This is especially true when the person with a disability is an adult and no legal responsibility to provide care exists. As informal care is often provided by members of the family, the term “Family carers” is often used synonymously with Informal carers.

In the European Union, over 80% of long-term care—understood as a broad range of services and assistance provided to people who, due to mental and/or physical frailty or disability over an extended period, depend on support with daily living activities or require ongoing nursing care—is delivered informally by family members, friends, or neighbours without formal pay or professional training.² It is estimated that approximately 52 million people across the EU provide such informal long-term care.³ These carers often assist with daily activities like bathing, eating, managing medication, and offering emotional support, most commonly within a home setting.

It is estimated that by 2050, almost one-third of Europe’s population will be over 65, with an increasing demand for health and social care⁴.

¹ <https://eurocarers.org/about-carers/>

² <https://wellcare-project.eu/new-report-release-examining-policies-support-for-long-term-care-providers-mental-health/>

³ https://employment-social-affairs.ec.europa.eu/document/download/41d72889-e608-4890-885c-9647a62c591d_en?filename=Flash%20report.pdf

⁴ https://www.oecd.org/en/publications/health-at-a-glance-europe-2024_b3704e14-en.html?utm_source=chatgpt.com

Many family members fill a gap in the social care system by leaving their jobs and providing often very intensive support to their children with multiple disabilities, or to their older parents with support needs. This is an important role to prevent the institutionalisation of people with support needs and without informal carers; formal health and social care systems would be overwhelmed and unaffordable. However, reliance on informal care is not a sustainable solution, considering the growing ageing population.⁵ With growing care needs and smaller family networks, stronger policies are needed to support informal care and prevent families from becoming overburdened. Recognising carers in social policy ensures the sustainability of Europe’s welfare and healthcare systems.

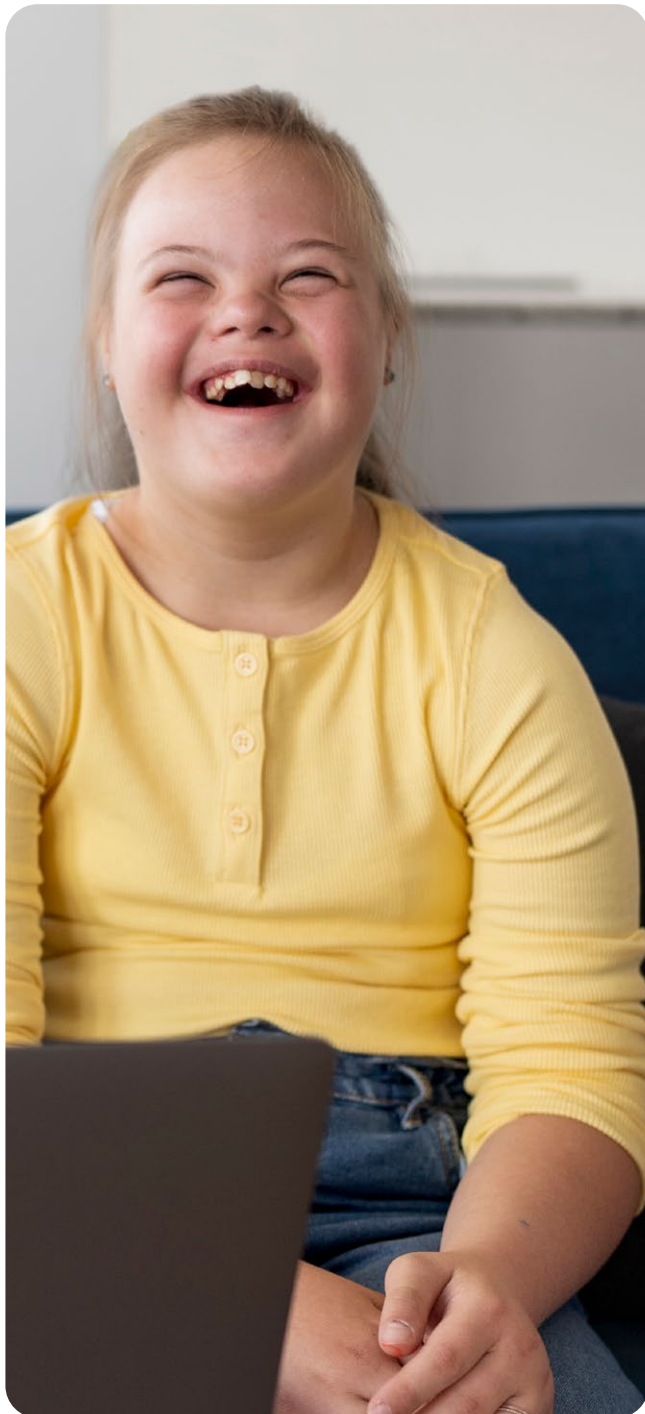
At a global level, Article 23 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) acknowledges the central role families often have in providing care. It requires States to assist them through services, financial support, and other measures, rather than leaving the burden solely on them.⁶ In the recent report, the Special Rapporteur on the rights of persons with disabilities, Heba Hagrass, highlights barriers faced by children with disabilities and their caregivers to the enjoyment of their human rights, in the absence of adequate support. She emphasises that the human rights of children with disabilities and their family caregivers are intrinsically linked. Children with disabilities have the right to grow up in a supportive family environment that ensures their well-being, development, and social inclusion. However, this right is undermined by systemic gaps in accessible, affordable, and community-based care, alongside policies that continue to prioritise institutionalisation.⁷

⁵ <https://wellcare-project.eu/wp-content/uploads/2024/10/WellCare-D4.1.pdf>

⁶ <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>

⁷ <https://docs.un.org/en/A/80/170>

In 2019, the EU Work-Life Balance Directive (2019/1158)⁸ introduces minimum standards to support informal carers, including **five days of carers' leave per year** and the right to request **flexible working arrangements**. Its objective is to improve carers' work-life balance and promote gender equality, recognising that women provide most informal care across the EU.



⁸ <https://eur-lex.europa.eu/eli/dir/2019/1158/oj/eng>

The European Care Strategy for Caregivers and Care Receivers was published in 2022,⁹ supporting the implementation of the principles enshrined in the European Pillar of Social Rights¹⁰, particularly the principles on gender equality, work-life balance, childcare and support to children and long-term care. It aimed to ensure quality, affordable and accessible care services across the European Union and improve the situation for both care receivers and the people caring for them, professionally or informally. This Strategy recommended to Member States: 1) to provide High-quality, affordable and accessible care long-term care and early childhood education and care services with better working conditions and 2) to ensure work-life balance for carers. In addition to International and European-level policy and recommendations, there has been substantial advocacy work by networks and organisations. For example, COFACE Families Europe in the European Charter for Family Carers (2017) highlighted that caregiving should be a choice, supported by affordable services that allow carers to reconcile work and care.¹¹ EurofamNet (The European Family Support Network), Eurocarers, and Inclusion Europe are instrumental in research and creating awareness of the issues faced by informal/family carers and to advocate for the changes recommended by research or indeed required by International, European and national policy and strategy.

Despite such policy, recommendations and advocacy, there remain concerns about the insufficient availability of accessible, community-based support services for children and adults with disabilities (and their families) across many Member States. This is particularly true when it comes to person-centred measures such as personal budgets, personal assistance, and support to access inclusive sport, leisure and social activities. Indeed, much of the previous research has focused on identifying the issues faced by families and the barriers to community living.

⁹ https://ec.europa.eu/commission/presscorner/detail/en/ip_22_5169

¹⁰ https://employment-social-affairs.ec.europa.eu/european-pillar-social-rights-20-principles_en

¹¹ <https://coface-eu.org/wp-content/uploads/2021/12/European-Charter-for-Family-Carers.pdf>

► Aim of the Study

The current, small-scale, study sought to extend previous work by exploring not only the issues informal carers experience but also the support they, or others they know, have received and found helpful or that would have been helpful if available. This was used to identify examples of Promising Practices in community-based support, with a particular focus on preventing institutionalisation and promoting dignity, well-being, community living and full inclusion of children and adults with disabilities and their families.

The research was guided by the following questions:

- ✓ Who is providing informal care and to whom?
- ✓ What approaches are currently used to provide support to families and other informal carers? Are approaches to support evidence-based?
- ✓ What are the key issues faced by families and other informal carers?
- ✓ What are the gaps in the current research and practice?
- ✓ What approaches, technologies and policies have helped informal carers to successfully support their child at home or an adult to live included in society and not dependent on family?
- ✓ What is needed to make such approaches a reality for more people?



► Methodology

Gaps in research

There is a general research gap in long-term care across Europe. A foremost concern is the lack of comprehensive and harmonised data on long-term care services, workforce, and financing. This includes limited information on both paid and unpaid carers, their activities, and the characteristics of care recipients, disaggregated by gender, age, socio-economic status, ethnicity, disability, migration, and legal status.¹² Informal care remains particularly under-researched.

There is also insufficient research on the availability and adequacy of long-term care services, especially home- and community-based care, and on how these align with the needs of carers and care recipients. The absence of robust quality assurance frameworks and consistent monitoring further complicates efforts to improve services. Moreover, there is a lack of studies assessing sustainable long-term care financing models and the economic value of carers' contributions.

COVID-19's impact on long-term care systems and carers has not been fully assessed, underscoring the need for new research to understand its long-term effects on health, service provision, and system resilience. In addition, the European Disability Expertise (EDE) project—supported and coordinated by a team of international senior experts in disability law, statistics, and policy, and working in collaboration with 30 national teams of independent experts—recommends that the European Commission encourage and support EU bodies and Member States to strengthen the disability-inclusiveness of disaster management and recovery frameworks, with particular emphasis on the effective involvement of organisations of persons with disabilities.¹³

Previous reports in this area have also identified gaps in the evaluation of the quality of services and checks on whether the policy is being implemented in practice. A recent study on the measurement of service quality indicated that data collected on quality rarely allows us to ascertain whether any state is progressively realising the UNCRPD articles (Šiška and Beadle-Brown, 2024).¹⁴

¹² <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

¹³ <https://op.europa.eu/et/publication-detail/-/publication/9bf9896f-79ca-11ed-9887-01aa75ed71a1/language-en>

¹⁴ <https://easpd.eu/publications-detail/study-on-service-providers-implementation-of-quality-approaches/>



Research approach

Annex 1 contains a detailed description of the methods used to conduct the research and identify the Promising Practices presented in this report. Figure 1 below summarises these methods into 4 stages.

Figure 1: Summary of methodology.



► Findings

Who provides informal care, and to whom?

In the European Union, informal care is predominantly provided by women, particularly those aged 35 to 65 and older. Women account for around two-thirds of informal carers. The majority are daughters, wives, partners, or daughters-in-law, though the role is also assumed by mothers, granddaughters, friends, and neighbours¹⁵. Carers often fall within the “sandwich generation” (ages 35–64), balancing care for ageing parents and young children. Some provide care for multiple individuals, with up to 27% of carers managing care for more than one person.¹⁶

In some countries, families rely on migrant domestic workers to fill caregiving gaps. For example, in Italy, three out of four home carers are migrants, often working under precarious conditions without adequate legal protections.¹⁷

Lastly, the COVID-19 pandemic underscored the essential role of informal carers across Europe, as healthcare systems became overwhelmed. Surveys found that during the crisis, the bulk of care continued to be shouldered by family members—especially spouses, partners, and adult children.¹⁸ However, long-term care models relying predominantly on informal carers (i.e. usually family members) are becoming unsustainable as the number of informal carers is shrinking (with more women entering the labour market, changes in family structures and depopulation of certain areas).¹⁹

¹⁵ <https://eurocarers.org/wp-content/uploads/2023/10/A-Lifetime-of-Caring-Who-Cares.pdf>

¹⁶ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-Families-Europe_Study-Family-Carers.pdf

¹⁷ https://eige.europa.eu/publications-resources/toolkits-guides/gender-equality-index-2019-report/informal-care-older-people-people-disabilities-and-long-term-care-services?language_content_entity=en

¹⁸ <https://eurocarers.org/publications/impact-of-the-covid-19-outbreak-on-informal-carers-across-europe/>

¹⁹ <https://employment-social-affairs.ec.europa.eu/document/>

What approaches are currently used to provide support to informal carers?

Informal care is formally recognised and regulated in some countries, such as Sweden, Denmark, Germany, Portugal, Finland, Austria, and Spain, while others, including Greece, Ireland, Latvia, Poland, Romania, Slovakia, and the Netherlands, have little or no legislation or systematic support for carers. In certain states like Latvia, Hungary, Lithuania, and Poland, adult children are legally obliged to care for older relatives, while in countries like Austria and Sweden, there is no such obligation.²⁰

Informal care remains a core part of many disability and long-term care systems, but the level of formal support for carers varies significantly. Some countries, such as Belgium, Germany, France, Luxembourg, and Malta, provide structured support through financial benefits, training, leave entitlements, and respite services. Others, like Greece, Ireland, Spain, Croatia, and Italy, continue to rely heavily on family-provided care with limited state assistance. The Netherlands promotes informal care culturally, but without legal obligations.²¹

Support for informal carers varies widely across EU countries, ranging from financial benefits to training, respite services, and work-life balance measures. Overall, support is often patchy and more developed for principal carers living with the care recipient.²² Financial assistance includes care allowances and tax credits. Personal budgets/ Direct Payments and personal assistance schemes

[download/41d72889-e608-4890-885c-9647a62c591d_en?filename=Flash%20report.pdf](https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1?filename=Flash%20report.pdf)

²⁰ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

²¹ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

²² <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

to provide care and support for a child and occasionally for an adult can also be paid to families in some countries, for example, in the Netherlands, in some regions of Belgium and in the UK.

Employment protection is offered through carer's leave and flexible work arrangements, with the EU Directive on Work-Life Balance (2019)²³ granting at least five days of leave annually. Countries such as France, Germany, Italy, Slovenia, and Sweden offer varying levels of paid or unpaid leave, job protection, and social insurance coverage. Similarly, the EU's Council Recommendation on Long-term Care (2022)²⁴ recommends financial support, access to respite services, training opportunities, work-life balance measures (e.g., flexible working hours and caregiver leave), and psychological support to prevent burnout.

Training and psychological support are offered in several countries, with some, like Germany, requiring formal training for families. Counselling, support groups, and wellness activities are available in countries such as Bulgaria, Portugal, Greece, Italy, and Sweden^{25 26}

Respite care is a form of support, provided through in-home, day services, and institutional services, providing temporary relief to carers. It plays a crucial role in supporting carers in countries like Denmark, France, Germany, and Portugal. Innovative initiatives provide creative respite solutions for family carers. In Belgium, Baluchon Alzheimer²⁷ sends trained professionals to stay with the person with dementia, allowing caregivers to rest without relocation, and Germany's Seniors Cafés offer a few hours of volunteers care for older persons for a few hours for older persons, giving family carers a break while promoting social interaction for the elderly.²⁸ Focus group participants also noted that schools

were important in helping families to cope, providing daytime respite, and sometimes allowing parents to work at least part-time. Civil society organisations play a crucial role in some countries, offering home help, information, advocacy, and peer networks.²⁹

Practical support is also common, including **parking permits, daily living assistance, and volunteer companionship**, with notable examples from the Netherlands, Luxembourg, Belgium, and Germany.³⁰

What do we know about the quality of informal care?

Quality evaluation in long-term care combines internal and external processes that vary by country. Internal assessments are conducted by providers, focusing on quality, safety, and service delivery, while external evaluations involve independent audits and certifications, which may be voluntary or mandatory, often for inpatient or residential care. Some countries apply comprehensive approaches; for example, Denmark uses multi-dimensional audits covering six dimensions and 12 indicators that measure both subjective outcomes, such as well-being and inclusion, and objective indicators like staff competence and documentation.³¹

In most countries, quality evaluation focuses on processes and the way services are run. Outcome evaluations, when these happen, they primarily focus on the health and safety (physical-well-being), satisfaction and occasionally the choice and control experienced by those receiving services. In Denmark, audits assess autonomy, habits, stability of care, and hospital admission rates. Austria uses the Adult Social Care Outcomes Toolkit (ASCOT) during home visits, while France is developing quality indicators for residential care. The

²³ <https://eur-lex.europa.eu/eli/dir/2019/1158/oj/eng>

²⁴ https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=oj:JOC_2022_476_R_0001

²⁵ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

²⁶ [COFACE-Families-Europe_Study-Family-Carers.pdf](https://coface-eu.org/wp-content/uploads/2021/12/COFACE-Families-Europe_Study-Family-Carers.pdf)

²⁷ <https://baluchon-alzheimer.be/>

²⁸ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-Families-Europe_Study-Family-Carers.pdf

²⁹ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-Families-Europe_Study-Family-Carers.pdf

³⁰ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

³¹ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

Netherlands incorporates service user satisfaction and informal carers' situations into its frameworks, and Sweden tracks waiting times, costs, medication practices, and user satisfaction through its "Open Comparisons" system.³²

Evaluation of informal care itself remains limited in many countries, with formal systems lacking in Spain, Lithuania, Hungary, Malta, and Poland. Austria assesses informal care quality during home visits for subsidy applications, while the Netherlands monitors carers' situations indirectly through broader quality frameworks.³³

What do we know about the quality of services designed to support informal carers or families of people with disabilities?

Overall, little is known about the quality of support services for informal carers or even for families of people with disabilities more generally. Formal evaluation of approaches and interventions, usually for families, has generally been qualitative in nature, looking at the perceived outcomes and experiences of those who received the services rather than measurable outcomes and impact that can be compared over time.

Broader outcome evaluations extend to care quality, carer well-being, workforce conditions, unmet care needs, gender equality, and the socio-economic impact of effective care. Quality discussions emphasise outcomes tied to social inclusion, independence, prevention, lifelong health, and a sense of purpose, supported by national frameworks, procurement standards, and certifications such as EQUASS.³⁴

Evaluations of some specific family support programmes have been conducted and published

³² <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

³³ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

³⁴ https://employment-social-affairs.ec.europa.eu/document/download/41d72889-e608-4890-885c-9647a62c591d_en?filename=Flash%20report.pdf

– for example, in Ireland, the Springboard project was evaluated with positive outcomes in terms of the children's psychological well-being and the parent-child relationships.³⁵ More recently, four different family support programmes in Ireland (the names of which were not identified in the paper, but they all primarily consisted of training for family members) were qualitatively evaluated. The important finding from this was that all four programmes were rated by families as helpful or very helpful – one programme was not seen as more helpful than another. Similar outcomes were reported across all four programmes in terms of "a changed mindset – a new way of thinking and being;" it makes "a difference within the family"; and provides a "locus for stimulating connection and belonging". There is no other research that compares different programmes or approaches to support evaluating whether any one is more effective or impactful than another. It is entirely possible that getting some support is the key.

Key issues faced by informal carers

Having choice over who provides your support is one of the key themes of long-term care and informal care-related policies and strategies. In regard to informal family care, the European Charter for Family Carers, written and updated in 2024 by the COFACE Disability Platform, states that people with care needs should always, and at any age, have the choice of receiving support from either a family carer or a professional carer.³⁶ Family carers should also have the opportunity to freely decide whether to fulfil caring duties or not, full-time or part-time, and to reconcile it with their work and personal life.³⁷

³⁵ Mckeown, Kieran & Haase, Trutz & Pratschke, Jonathan. (2006). Evaluating Springboard: Impact of a family support programme in Ireland. *Journal of Children's Services*. 1. 16-28. 10.1108/17466660200600003.

³⁶ <https://coface-eu.org/european-charter-for-family-carers/>

³⁷ https://linkprotect.cudasvc.com/?url=https%3a%2f%2fcoface-eu.org%2feuropean-charter-for-family-carers%2f&c=E.1JXbGik4TKJMMhDjx1aVerQ8XZ1znm4CtU9u6j3c8HZ__W1osrjFovzYZR6M37R7Suk32Z_VxDwciAYZ_pmAilv4qIEqj4QeFj6L_L6DvDNZO4q05OoE.&typo=1

However, despite attention in EU policy and in disabled people’s organisations (DPOs) and non-governmental organisations (NGOs) reports, care systems remain imbalanced, and choice is rarely the reality. In many countries, entitlements in terms of support for families are unclear, and thus uptake is often low. In addition, coverage is limited, especially for groups such as the self-employed. In countries like Sweden, Italy, and the Netherlands, support is often determined locally, leading to significant variation. Civil society organisations frequently fill gaps, especially in mental health and well-being support. As the ageing population grows and the number of informal carers declines due to demographic and labour market changes, heavy reliance on family care is becoming unsustainable.³⁸

Table 1 summarises the challenges and issues faced by informal carers, in particular family members, as identified in the literature review.

Table 1: Overview of challenges faced by informal carers, drawing on the literature review.

Themes	
Emotional, social & mental health challenges	<ul style="list-style-type: none"> • Stress and burnout: Continuous care can lead to chronic fatigue, emotional exhaustion, and even caregiver burnout; • Anxiety and worry: Concerns about the family member’s health, future, and long-term care needs; • Depression and isolation: Feelings of loneliness or hopelessness, especially if social activities become limited; • Family tension: Disagreements among relatives over care responsibilities, decisions, or financial contributions; • Loss of personal identity: Caregivers may feel their own life goals, hobbies, and relationships are on hold;
Physical strain	<ul style="list-style-type: none"> • Physical exhaustion: Assisting with daily activities can be physically demanding; • Sleep disruption: Especially for caregivers of individuals who require nighttime supervision or assistance; • Health neglect: Caregivers may ignore their own medical needs due to lack of time or energy.
Financial challenges	<ul style="list-style-type: none"> • Loss of income: Caregivers may reduce working hours or leave jobs entirely; • High care costs: Medical equipment, therapies, medications, and home modifications can be expensive; • Limited financial aid: In some places, disability benefits or government assistance may not cover actual needs.

³⁸ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-paper_Families-dimension_v4.pdf

Themes	
Logistical & practical challenges	<p>Complex healthcare systems: Navigating medical care, insurance, and disability services can be overwhelming;</p> <p>Time management: Balancing caregiving with work, parenting, and other responsibilities;</p> <p>Access to support services: Limited respite care, transportation, or specialised programs in some areas.</p>
Future uncertainty	<p>Long-term care concerns: What happens when the caregiver can no longer provide support;</p> <p>Legal and guardianship issues: Planning for decision-making, trust funds, or supported living arrangements;</p> <p>Fear of inadequate care: Worry that the family member might not receive the same quality of care outside the family.</p>

Financially, carers face high costs – especially in countries where they have to pay for therapy for their family member with a disability, strict means-testing, and significant out-of-pocket expenses. Many experience income loss, reduced pensions, and a heightened risk of poverty.³⁹ This is particularly true for women. Balancing paid work with caregiving is difficult due to insufficient leave as well as a lack of flexible arrangements or employer support, leading many to reduce hours or leave the labour market entirely, which exacerbates financial insecurity for the present time, same as for the future.⁴⁰ In the focus groups, the term “precarious” was used to describe families’ financial situation. Families were often stuck in the poverty trap and frequently depended on the individual’s disability pension to survive – this was a disincentive for families to encourage/support adult children to live independently from family.

³⁹ Watkins M, Overton L. The cost of caring: a scoping review of qualitative evidence on the financial wellbeing implications of unpaid care to older adults. *Ageing and Society*. 2025;45(7):1465-1492. doi:10.1017/S0144686X24000382

⁴⁰ Lilly MB, Laporte A, Coyte PC. Labor market work and home care’s unpaid caregivers: a systematic review of labor force participation rates, predictors of labour market withdrawal, and hours of work. *Milbank Q*. 2007 Dec;85(4):641-90. doi: 10.1111/j.1468-0009.2007.00504.x. PMID: 18070333; PMCID: PMC2690351.

In addition to low income, carers often lack legal recognition, social protection, paid leave, and pensions, and face low societal recognition, bureaucratic obstacles, and stigma.⁴¹

Health and well-being are also at risk. Carers face high rates of stress, depression, fatigue, and social isolation, with intensive caregiving increasing mental health problems. The prevalence of mental health problems among informal carers is 20% higher than among non-carers, and particularly high for people who provide very intensive care (more than 20 hours per week).⁴² In focus groups, families and service providers both mentioned the social isolation faced by families, particularly by mothers, but also mentioned that fathers are often forgotten and have different needs and issues.

Beyond the direct caregiving tasks, families face an additional and significant burden in navigating and managing support systems. Focus groups highlighted that families often spend substantial time looking for, fighting for, and, if successful in accessing services, they often have to coordinate

⁴¹ <https://op.europa.eu/en/publication-detail/-/publication/b39728e3-cd83-11eb-ac72-01aa75ed71a1>

⁴² https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Intro_final.pdf



all the services and professionals involved. One participant noted that “Life is like a fight”, and another father commented that families “Need a project manager...Families should be quality control, not the director of services”.

Workforce shortages and poor working conditions in formal care cause issues for families. Even when families have access to formal care, e.g. through personal budget/assistance schemes, they often find it hard to recruit and particularly to retain assistants for their family member. Low pay and hourly contracts are a particular issue. The term “precarious” was also used to refer to the situation of workers in the disability field – for example, “precarious contracts” and “precarious” financial situation for workers were seen as resulting in substantial turnover. One sister noted of her brother, “he has had 7 or 8 different people in the last 18 months”. In some countries, such as Slovakia, staff often move to Austria or Germany as there is better pay, and they can often speak the language enough

to manage. One participant described those who work in care as having a “big heart” but are often burnt out and are not earning enough money to pay their bills. This is not just an issue in Europe but in many other countries, where those who work in services often must work three jobs just to live – not only is this not good for the carers, but it is also not good for the individual and family supported, as inevitably the quality of support will deteriorate in this situation.

The COVID-19 pandemic worsened these impacts, leaving most carers feeling unsupported.⁴³ Access to respite and specialised services generally remains limited, particularly for families caring for children with more severe or complex support needs or people with severe mental health needs.

⁴³ <https://eurocarers.org/publications/impact-of-the-covid-19-outbreak-on-informal-carers-across-europe/>

A range of other issues faced by families was also identified in the focus groups. These included:

1. The lack of accessible information for families at all stages in the development of their child and in the service utilisation journey. This was particularly an issue at birth/diagnosis and at transition points. It was frequently hard for families to find out where to get information, and they had to go looking – there were very few proactive approaches to providing information. Even families with knowledge of the system due to their own job or training and knowledge of the law struggled to get their own children support. “Even I struggled.”

2. Silo working in services – professionals, agencies, and services rarely work in collaboration/partnership to make it easier for families. As noted above, families are often left to “manage” what can be a myriad of services and professionals, especially when people have complex health needs in addition to their disability.

3. Lack of person-centred, whole life planning and support, especially related to transition to adulthood. Participants in focus groups noted that there was a lack of continuity of support, with one parent noting that in Italy, “you would think he was the first in the world to turn 18”. Another participant in Spain commented that their relative could go to a sheltered workshop until they were 52 and then were forced to leave with nothing to replace it. And several parents of younger children talked about the summer holidays as a “total disaster.” Lack of actual transition preparation and support was also reported. “He finished school last week. We only found out on Thursday what support he is going to get next year.” The fact that planning was often left to the last minute, if it happened at all, especially at times of transition. Planning for when families might not be able to provide support was also rather rare.

4. A key issue, raised by almost all participants in all countries, was **the attitudes and working practices of professionals**. Although some families had good experiences with some services and professionals, many experienced medical model thinking – approaching disability or care primarily as a medical problem, suggestions to euthanise their disabled child, silo thinking and “well-meaning but disorganised”, chaotic, reactive approaches from professionals, with some even experiencing pressure to institutionalise their child at 1 year old. As a rule, services and health and care agencies focused on care and protection almost entirely, with little attention paid to positive outcomes.

5. Low expectations, particularly for those with intellectual disability, were a major issue. Families talked about having a label of an intellectual disability being equated to having “no potential”. School is often childcare, not education. Opportunities for real work are very limited and

6. Lack of training for families was identified by many focus group participants. In particular, it was noted that training that helps families gain a positive perspective of their child and a possible future and have strategies for supporting the quality of life of their child, was rarely available.

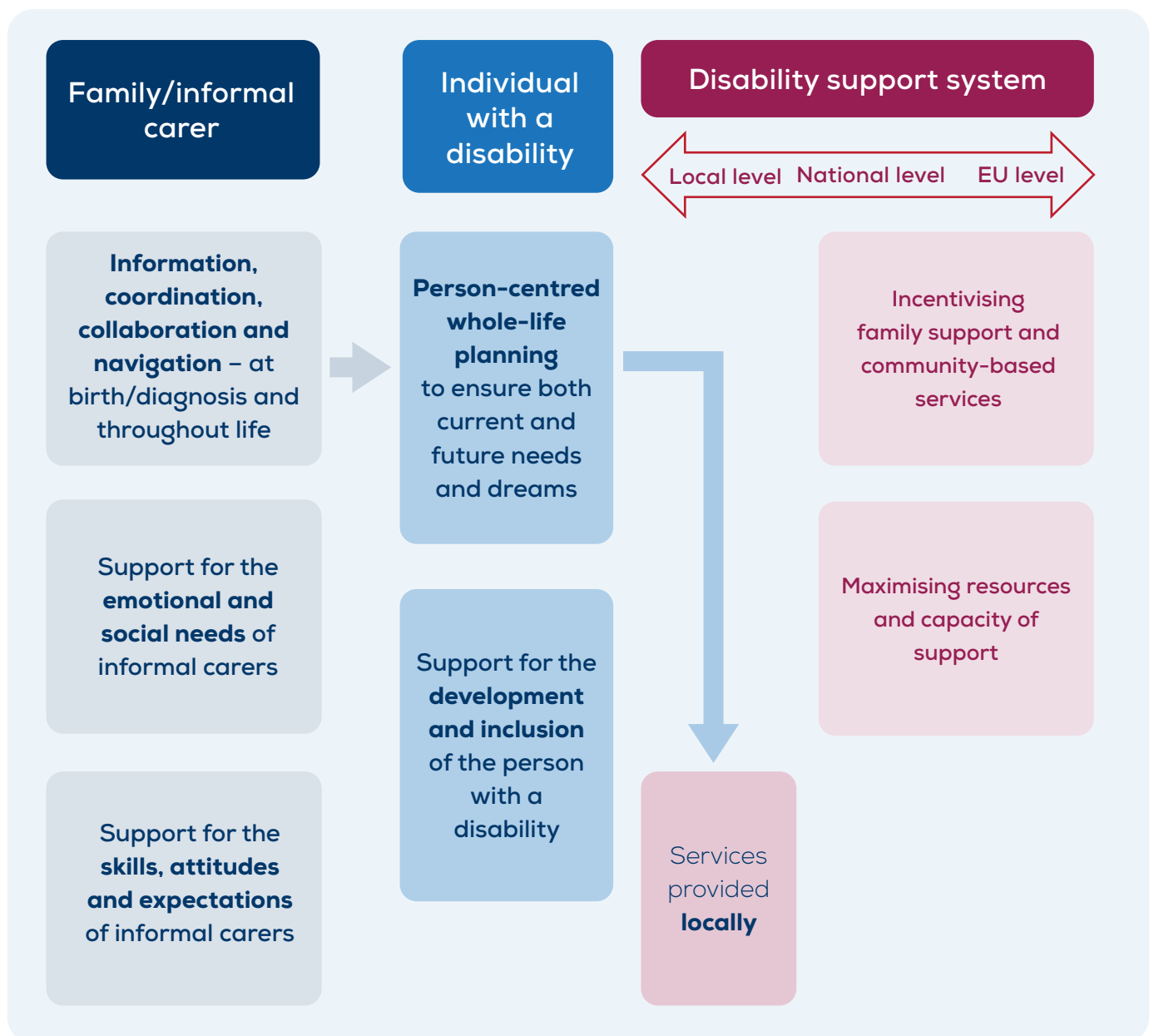
7. Lack of community-based options for support was also an issue in many countries – in some places, institutions were the only option if families were struggling to cope. Even small group homes were not an option in some countries, and where there were group homes, there were as many as 10 people in one house, which limited the quality-of-life outcomes possible. Lack of affordable and accessible housing options was also an issue for adults with disabilities living independently. One participant described how many buildings are still not accessible, and people with disabilities are often “imprisoned” in their own homes, as they cannot leave their apartments due to accessibility issues.

Supporting informal carers and helping children at home and adults to live in society without family dependence

Focus group analysis identified several approaches and technologies viewed as helpful by informal carers and service providers. Some policies were also mentioned, though challenges in implementation were noted. Approaches found effective in certain countries were often highlighted as needed in others. Overall, these findings reflect potential solutions to the issues outlined in the previous section.

Figure 2 provides a summary of the themes raised and approaches identified as helpful. There were three levels of approach identified – those at the level of families and informal carers, those more focused on individuals with disabilities and those at a systems level. As can be seen, several approaches went across levels or informed processes at the next level.

Figure 2: Summary of the themes raised and approaches identified as helpful.



The importance of information, coordination, collaboration and navigation throughout life

Being provided with information was discussed in all focus groups as key – this included information about their family member’s diagnosis and the support they might need; information about their rights and the rights of their child; information about the services available to their child and how to access these as well as how to access support for themselves; how to access and what they need to be aware about in terms of benefits. Receiving information was particularly important and helpful if done early – soon after birth or diagnosis – but was important at all points in life and particularly at transition points or at times where decisions were needed.

However, to be most effective, the information needed to be provided in a coordinated and consistent way – ideally one information source with everything in it, having been checked that the information was consistent, up-to-date and accessible. Coordination between services involved with a child and their family and with a young person, especially as they move into adulthood, was critical throughout their own life journey.

The issue of silo working caused significant stress for individuals and families, and collaboration between agencies involved at all points was highlighted as very important and very helpful when it was experienced. Collaboration between agencies of different types and the families and individuals themselves as adults was also viewed positively.

Finally, participants in the focus group talked about the need for more navigation support for families, to reduce the burden of having to find out everything themselves, and to make it easier for families of children with disabilities to have similar opportunities and access to family life, employment and social connection as other families. Navigators helped guide families and individuals through diagnosis, applying for social security or services, identifying other sources of support, looking for housing, etc. In some cases, navigation services were simply signposting; in other cases, they provided more direct support and advocacy. Financial and benefits advice, either provided by navigators or by other trained professionals, was important throughout a family’s life care journey, but particularly at diagnosis and at points of transition.

Supporting the emotional and social needs of informal carers

In all focus groups, the importance of peer support and social connection for families was highlighted. Both formal and informal sources of support were identified as important – for example, some services helped families to connect and have time with families and friends through respite, etc., while others provided opportunities and structure for families to meet and exchange experiences through family support groups. Being able to respond to gender-specific and cultural needs was seen as important, as well as working with the whole family, including siblings, grandparents, etc.

Supporting the skills, attitudes and expectations of informal carers

The need for and importance of training for families, as soon as possible after diagnosis, was raised in all focus groups. Most commonly mentioned as helpful was training to help informal carers reframe how they thought about their child with a disability and attitudes towards disabilities more generally, and to help them imagine a more positive future for themselves and their child. Training to understand their rights and the rights of their family member or friend was also identified as helpful.

Supporting the development and inclusion of the person with disability

A range of therapeutic services were identified as important, particularly at diagnosis, but also right through life – for example, access to occupational therapy, physiotherapy, and speech and language therapy was provided in some countries as a matter of course, although sometimes limited in the amount of time for which such support was provided. Of course, receiving the appropriate health care from empathetic and knowledgeable medical professionals was also identified as key.

Schools and colleges were seen as important both as a form of respite for families, but also as a way of providing the educational input needed to help children and adults reach their potential and be as independent as possible. However, finding schools that did more than provide “childcare” for children with severe and complex needs was a challenge in most countries.

Respite, short breaks and activities that give opportunity for friendship and integration were needed and helpful for as long as the person is living with the family. Sport (especially if accompanied by opportunities for social interaction afterwards) was seen as a very important route to inclusion, friendships and physical well-being, although such opportunities

appeared very limited. Opportunities were particularly limited for children and adults with higher support needs, particularly for adults.

Another approach found helpful by families of young adults was support and living arrangements that helped to develop independence from family at an earlier stage – for example, holiday camps, shared care services and opportunities for young people to visit other relatives and friends without their families.

Mainly for adults, the importance of more employment support services was highlighted but with the additional point that these needed to take a much wider remit than traditionally and been the case and be willing to support adults with disabilities in lots of different types of jobs and settings, including customised employment, social and micro enterprises, self-employment, voluntary work as all these are valid ways for people to have meaningful lives and to give people more experience to help them gain competitive and integrative employment.

Finally, if adults with disabilities are going to be able to move out of the family home when they want to do so, then there need to be many more creative solutions to the lack of (affordable, adequate, and accessible) housing in the community. However, access to affordable, adequate and accessible housing was important for families since too many families of people with disabilities live on the poverty line and in inadequate housing.



Using person-centred, whole-life planning to ensure both current and future needs and dreams

Whilst the need for *person-centred* approaches to planning was highlighted, what was seen as even more important was that any planning was *all-age* and *whole-life* – i.e. it went across all elements of the child or adult's life and continued to be developed and expanded on over time. For children, it was also important that planning was a *whole family* affair, too. We heard about one or two examples of such planning systems being piloted, usually in projects with short-term funding, but this was something that, overall, was identified as needing much more work. One example was the “Progetto di vita” in Italy, where young people with disabilities and their families were supported to develop an individual person-centred plan which focuses on their whole life, not just their services. Originally a pilot project, this approach has now been embedded in policy. Such holistic planning that goes across all life transition points and starts the process of future planning as early as reasonably possible was also highlighted as key for identifying local service needs and supporting local and regional strategic planning.

Providing services locally

Identified as something that would have helped much more than most informal carers experienced was the fact that if services and schools were provided in all localities and not situated far from the main community. The local proximity of services would not only help families to continue to care for a child with a disability at home but would also support children and adults with disabilities to be more included in their community, alongside their family members and friends.

Incentivising family support and community-based services

Some helpful schemes (particularly funding schemes) were noted by focus group participants as helpful for encouraging families to keep children and young people with disabilities within the family home. However, it was noted that even when funding through personal assistance, personal budgets schemes, and carers budgets was available, there were not always services to purchase. It was highlighted that more schemes are needed to incentivise service providers to deliver services for informal carers and to prioritise and incentivise community-based services over more institutional models of care. This was seen as particularly important when it came to encouraging more service providers to develop short and long-term services in the community for children and adults with higher support needs and/or complex medical needs.

Maximising resources and the capacity of support

There were several things that were identified by families as important and much needed, although rarely experienced by focus group participants and those they knew. Where support was more personalised and flexible so that it could be adapted to meet the needs of children, adults and families over time, this resulted in much better outcomes and experiences.

Whilst some people mentioned the fact that more funding overall would be helpful, others highlighted countries or systems where funding followed the person (rather than being allocated to services to support X number of people) and services designed around the individual as being more efficient. This was in contrast to where people with disabilities were “pigeon-holed” into whatever services currently existed, even if they were not the right services for that person or family. In this system, people were often provided with too much support, thus preventing their development and greater independence.

The final area that was seen as important to develop if children and adults with disabilities were to live included in their family and community was the issue of the workforce – better pay, contracts and conditions, as well as more and better training for those who support individuals with disabilities and their families was seen as key to have a more stable and skilled workforce. Training for the medical and other (usually higher-paid) professionals was also identified as helpful, particularly to change attitudes and build positive expectations.

In conclusion, focus groups with informal carers and service providers across countries revealed the urgent need for more coordinated, accessible, and person-centred support. Families highlighted the importance of timely

and consistent information, navigation support, and collaboration between services, particularly at diagnosis and transition points. Peer support, respite, and culturally sensitive family programmes were seen as critical for carers' well-being. For people with disabilities, access to therapies, inclusive education, community activities, employment opportunities, and affordable housing were identified as vital for independence and inclusion. Families also called for early training to build skills and positive expectations, whole-life planning to guide service development, and funding models that prioritise flexible, community-based care over institutional approaches. Finally, a stronger, better trained, and fairly paid workforce was seen as essential to deliver quality, sustainable support for both carers and people with disabilities.



Promising practices

The following ten areas of promising practices were acknowledged from the thematic analysis of data gathered from focus groups with informal carers.

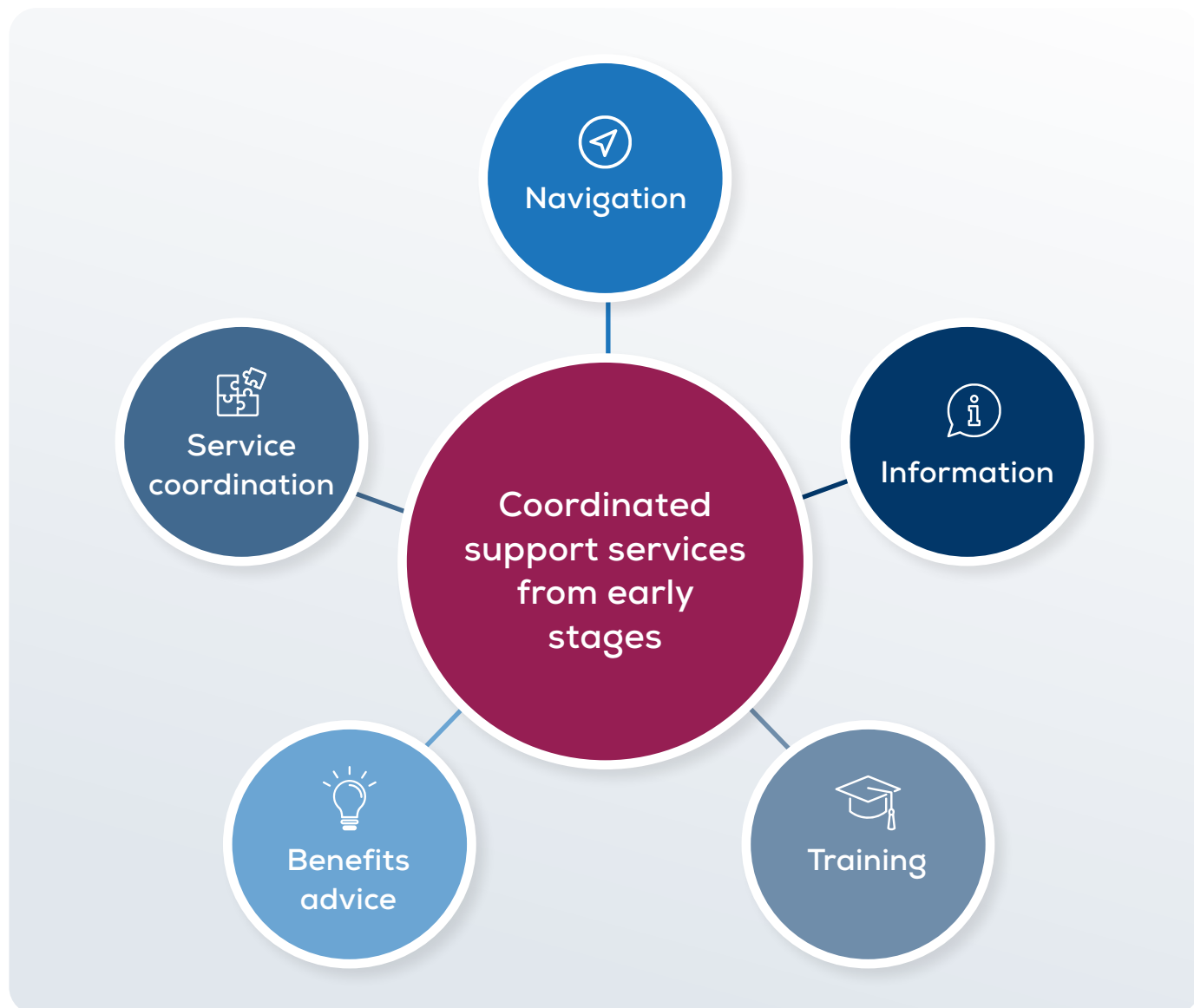
The intention was not to produce an exhaustive list but rather to identify examples that illustrate what is already being done in each area. These examples were drawn from the informal carer focus groups, the focus groups with service providers, the literature review, and the researchers' own experience. Annex 2 lists the examples in each area of promising practice, along with the source or further information where available.

Figure 3: Areas of promising practices acknowledged.



1. Co-ordinated [early] support services (from birth or diagnosis) - Information, navigation, training, benefits advice and service coordination.

Figure 4: The different components that were highlighted under this area.



The importance of information, navigation, training, benefits advice and service coordination was highlighted in the previous section. When these happened in a coordinated and proactive way, right from birth/diagnosis and through each ensuing transition point, this was seen as particularly helpful for families, especially when a child (or adult) had multiple or complex support needs. There were few examples of how all these things are brought together in one system, but several examples of elements of promising practices in this area were identified by the focus groups, by stakeholder review and by review of online resources. For the most part, these examples related to support early in childhood or immediately post-diagnosis.

Example 1.1: In Greece and the UK, all families are provided at the birth of their child with printed or electronic Child Health booklets, which not only provide space to record appointments, vaccinations, and developmental markers but also provide more general **information** about what to expect at different developmental milestones and where to get help if there are concerns. These booklets are used by all professionals involved in the child's life, thus allowing information to be shared and increasing consistency between professionals (**Coordination**).

Example 1.2: In Finland, the national online service Omapherhe provides a website resource for all families, which includes information on what families need to do and what support is available if they have a seriously sick or disabled child.

Example 1.3: In Switzerland, families of children with disabilities are proactively provided in the first couple of days after the birth of the child, often when the mother and baby are still in hospital, with an information pack about services available to them and who to go to for help.

Example 1.4: In Oregon in the US, the State provides a Family Carer Support Program that provides informal carers with information, help to access services and support, legal assistance, advice, counselling and respite care all "under one roof". The program also provides a Family Caregiver handbook and Caregiving Guides online.

Example 1.5: In Italy, Anffas, the National Association of Families and People with Intellectual Disabilities and Neurodevelopmental Disorders, provides a very comprehensive website with information and resources and training for families.

Example 1.6: Portugal has long been a source of good practice in terms of transdisciplinary early childhood intervention services, which support families to access services and benefits while at the same time supporting the child to develop skills in their natural environments and during daily activities. Coordination is provided within the transdisciplinary team by the appointment of a Case coordinator. Other countries are also beginning to develop or expand their early intervention and advice services for families.

Example 1.7: In Bulgaria, the Karin Dom Foundation now provides a wide range of therapies for children and support and training for families, all under one program. This was part of the Child Guarantee pilot.

Example 1.8: A new early intervention and advice service based in a community centre in Slovakia was also highlighted as innovative in that a whole family approach is taken to assessment and support, as well as ensuring people's cultural and linguistic needs are taken into account.

Example 1.9: The Foundation Paideia in Italy not only provides information, training and emotional support for families (including siblings) but, like Portugal, they work with a "Team around the child" approach where a transdisciplinary team of professionals, including psychologists, psychomotor therapists, speech therapists, social workers, physical therapists and occupational therapists all work together with the family to ensure adequate and appropriate support.

Although in its infancy in some countries like Slovakia, other countries have more established systems of case management or service coordinators (for example, most US states and Portugal). This role is usually responsible for assessing the needs of individuals and families and putting together a care package. However, most service coordinators and case management roles are not cross-sector – for example, they tend to be based in health or in social care. Nor do they often go across childhood and adult services. In some systems, case management is a service provided by an NGO (and thus independent of the funder of services), but in other countries, service coordination is provided by the same agency that funds services, which is sometimes argued as producing some conflict of interest.

An alternative or additional approach to supporting families that usually brings some independence and that informal carers reported as particularly helpful was that of a system of service navigation.

Example 1.10: In some counties in England, Children’s Health and Well-being Navigators are identified for children early in life, especially if any developmental or health concerns emerge. Navigators signpost families to relevant services and support them through diagnostic assessments.

Example 1.11: In California, there is a Community Navigator Programme that works in partnership with the Family Resources Centers Network of California. Community Navigators work 1:1 with individuals and families, providing support to access and use services. There is also a service called Coordinated Family Support that works in a similar way to support adults with developmental disabilities who live in the family home.

Example 1.12: In Italy, there are also examples of “digital navigation” tools developed by civil society, such as AreAto.org, which provides accessible information in a portal that maps services, rights, and opportunities for families with disabilities, essentially acting as a social navigator and empowering families with clear guidance.



2. All-age, whole-life, person-centred planning

The need for whole life planning (e.g. across health, education, care services, leisure, relationships, etc) and ideally from birth to the end of life was identified as needed. “Whole family” planning was also important, particularly for children. As noted in the previous section, such planning needed to be person-centred and positive/strengths based.

Example 2.1: In the UK and Ireland, person-centred planning for adults with intellectual disability is required in policy and in Sweden, there are also good examples of person-centred planning for those with intellectual disability.

Example 2.2: In Italy, there are several new and emerging initiatives that are some of the first to implement whole life planning. Following a pilot project over the past few years, policy makers are developing a policy framework to promote person-centred, strengths-based, life-long planning (“Progetto di vita”). The Individual Life Project will give people the right to a personalised plan co-produced with family and services. In addition, another decree connects an Individual Education Plan to broader life plans, whilst the law Dopo di Noi (After Us) funds supported living and life projects when families can no longer provide support.

Example 2.3: A similar project in the Netherlands (A Rich Inclusive Life) supports people with disabilities and complex support needs to co-design their lives with family, community members and professional supporters. In addition to the planning process, assistance is provided via Personal Budgets, which allow individualised care arrangements.



3. Social and emotional support and connections - for parents, siblings and the whole family

Example 3.1: In Ireland, several different organisations provide the Springboard Family Support project in several cities. They provide support for families more generally – training, counselling and support groups – but target those who are at risk in some way – for example, of homelessness, exclusion, etc.

Example 3.4: In Oregon, US, the Bring Fathers Forward program is one example of a program that provides specific support for fathers.

Example 3.5: The Sibling Support Project in the US and the Siblings Australia Inc. provide support and training for siblings of children with disabilities.

Example 3.6: In Italy, Fondazione Paideia provides empowerment and connection support to combat isolation and promote self-help/solution-finding. It organises peer group discussions for mothers and fathers separately, recognising their different needs. Informal support for families is offered during activities for children. A Carer Stress Group (with mixed ages of children) benefits both families of older children, who can see how far they have come, and families of younger children, who gain hope for the future. Additional initiatives include peer support for siblings and combined summer camps for children and their siblings.

However, social and emotional support is primarily provided by Disabled People's Organisations and NGO/civic organisations focused specifically on families of individuals with disabilities.

Example 3.2: The Platform of Families and Children with Disabilities in Slovakia and Karin Dom Foundation in Bulgaria provide peer support to families and children, with support from professionals as needed.

Example 3.3: In Greece, the Greek Parent Association for the Supported Living of People with Intellectual Disabilities provides emotional well-being support and advice to families to help them prepare for the transition of their family member to supported living, as well as a sibling support group and general information and education for families on disability issues.

The need to provide specific support for different members of the family is reflected in some of the examples of promising practice.



4. Personalised, flexible, creative funding and assistance/support

Having funding that follows the person and a system where small providers work together to meet local needs were two ways that were seen to be useful to help people get just the support they need to help them experience a quality of life similar to others without disabilities. In many countries in Europe, personal budgets, public funds allocated directly to an individual, rather than to a service provider, to give the person greater choice and control over the support they receive, and personal assistance are now available at least as a pilot. Notwithstanding some of the issues mentioned in earlier sections, some promising practices exist.

Example 4.1: In Finland, personal assistance is a right for people with severe disabilities under the Disability Act, to support independent living by assisting with everyday tasks and enabling participation in society. There are three different options for how personal assistance can be managed/received, which can also be used in combination, thus giving flexibility and choice of individuals: 1. The employer model (64%), in which the local government covers the cost and the person receiving services directly employs the personal assistant; 2. The Voucher model (3%), in which those who receive services are given vouchers by the local government to use to purchase assistance services; and 3. Assistance service (24%): this service is provided by the local government or purchased from a private provider. In Finland, there is also a carer's allowance for families of children with disabilities. Other examples of personal budget projects are available in Salzburg, Austria, and Lebenshilfe, a national association supporting persons with intellectual disabilities, also has a personal assistance project.

Example 4.2: In Scotland, Enable Scotland, a national non-profit organisation advocating for and supporting people with learning disabilities, developed, piloted and evaluated the Personal Assistance model in response to the Self-directed Support (Scotland) Act 2013. The model supports people to have control over their personal budget and how it is spent, but without the need for people to become employers. Small bespoke staff teams are chosen by the individual and contracted directly with them.

Other examples of creative funding and ways of assisting families to provide support are seen in Italy, where the law protects the rights of people with disabilities and their families, including the provision of benefits such as paid leave and time off work for workers with disabilities or their family carers; tax breaks for purchases of goods and services (such as care and aids) and priority choice of workplace.

Example 4.3: The Undivided platform in the US provides support to employers of informal carers of children with disabilities so that families can keep their jobs (and therefore keep income coming in) and employers can retain a valuable workforce.

5. In-home respite, leisure, sport and opportunities for participation, friendship and inclusion

Promising practices in this area ranged from informal, individualised arrangements drawing on natural supports and community organisations to large-scale schemes such as Special Olympics Unified Sports. Examples of opportunities for increasing participation and inclusion (as well as more general well-being) included playing sports and joining in associated social activities (e.g. going to the pub after the game) and becoming coaches/trainers of sports for children.

Example 5.1: In Austria, this is taken to a higher level with the inclusion of people with disabilities in the Sports Management Assistants programme, which trains people to work at Sports Events in different roles.

The visual and performing arts (theatre, music, dance) are the source of many examples of inclusive activities – for example, the Nevronas Festival in Greece, the All Inclusive project in Bosnia and Herzegovina, LASSO in Belgium and SavasRock in Finland.

Although respite or short breaks services were often seen to be in short supply and not as flexible as families always needed, one example of a service that was seen as really promising was the Tukena Foundation's Family Relief Service.

Example 5.2: In Finland, the Tukena Foundation Family Relief Service consists in short-term care in the family home for individuals with disabilities and siblings to give informal carers a moment of rest and allows them to have an existence as an individual, not "just" the parent of a child with a disability.

Example 5.3: In Italy, the Fondazione Paideia provides recreational and creative activities, both inclusive and disability specific, as well as a range of inclusive sports activities for all the family, which aim to not only promote exercise but also promote autonomy, fun and new relationships.

Example 5.4: Finally, every year, the Estate Paideia runs vacation weeks for families to participate in a wide range of activities with support from volunteers to help with care activities during the stay. The family can give time and attention to the child with a disability that is not focused on health and care but on having fun, as well as giving attention to siblings, who also have lots of peers with which to interact.



6. Services that support development of skills and transition to adulthood – shaping up independence for both families and the person with disabilities

Opportunities for the young person with disability to be away from home, even for a weekend of activity and connection with other young people, were seen as opportunities that prepared young people (and the families) for independence in a way that felt manageable for both. Examples included initiatives such as holiday camps (both specialised and inclusive) in Italy and in the US.

Example 6.1: The Fondazione Paideia in Italy provides immersive residential weekends referred to as Piani di Volo (Autonomy and Future), where young people with disabilities can practice daily living skills in a safe but realistic environment. Participants get the opportunity to take part in a range of experiential programmes (e.g. educational circus, mindfulness and cooperative play) as well as to participate in farm activities and daily routines.

Example 6.2: The Fattoria Sociale Paideia provides opportunities for young people to take part in agricultural activities, workshops and animal care – providing practical, social and professional skills in an inclusive environment.

Example 6.3: In Belgium, the Breakout project, run by the NGO Konekt, supports young people to identify their skills and plan for their future, thus supporting their transition to adulthood. In Flanders, the possibility of “shared care” services, where young people lived at home with the family 4 days a week and lived in a small group living setting the other 3 days, was felt to be indeed helpful for developing skills and experience that ultimately promoted independence.

Example 6.4: In Greece, there were two important initiatives – one was already mentioned – the Greek Parent Association for the Supported Living of People with Intellectual Disabilities, which supports people with disabilities and families to transition to supported living. The second is the Margarita Vocational Training Centre (VTC) programme, which prepares people with intellectual disabilities to live independently in the future, transitioning either to community-based arrangements or to their own apartment. For some, the focus is on helping them avoid institutionalisation later in life, even if they remain living with their family in the short and medium term.

Future promising practices in this area are likely to arise from the new Inclusive Path Project, launched in 2025 to support more young people with intellectual disability into post-secondary education. This will be achieved by training teachers and other staff in Secondary Education (SE) and PSE, and by empowering families and children with IDD, particularly in making decisions related to transition to adulthood.

7. Progressive and customised employment support

It was acknowledged that work is important, and job coaches are needed, as well as support to complete voluntary work or work placements, etc, helping to build job skills and experience.

Although related to the development of skills and transition to adulthood, promising practices in relation to progressive and customised employment support were seen as important in and of themselves.

Example 7.1: In France, the Support Apprenticeship system by LADAPT Association, is designed to support the transition of people with disabilities to work through apprenticeship contracts. This system is considered unique in how it works with the entire ecosystem revolving around the person, making it possible to support not only the person themselves but also the employer and training centre.

Example 7.2: In Germany, the NGO Zukunft Trotz Handicap helps individuals (primarily those from underserved groups and those who have previously only experienced sheltered workshops) to gain training and experience that will help them get a job in the open market. They provide two new qualifications – a daycare training programme to support people into work in childcare and the gastronomy training programme, which supports people into work in hotel, catering and housekeeping jobs. An important part of these programmes is that they include internships as well as classroom-based/theoretical elements. Members of staff on the programmes work closely with participants to find suitable organisations and companies based on their existing skills and interests, facilitating their transition and integration into the workforce. To make this happen, the organisation-built partnerships with various stakeholders and potential employers.

There are other examples of programmes that provide **internships or voluntary work support** to help people with disabilities gain professional skills and work experience – for example, the I FormidAbili project involving Leroy Merlin and Fondazione Paideia in Italy. Another example is Werkburo in Belgium and the service provider, Hubbie in Brussels, who have helped around 40 clients to find voluntary work, which is recognised as a useful stepping stone to paid work.

Example 7.3: In Finland, vocational rehabilitation services provided by the state help people to get and keep jobs through job coaching.

Example 7.4: In Greece, the Margarita programme mentioned above includes support for people to transition to work, increasing the possibility for independent living.

8. Creative solutions for housing in the community

Previous work by EASPD⁴⁴ and other organisations have identified promising practices related to supporting the transition of people with disabilities to live in the community. However, lack of adequate, affordable and accessible housing has been identified as a key barrier to community living both in the focus groups conducted for this project and in previous research. Previous examples of promising practice did not identify solutions to housing issues, and so as such that is what we have focused on that here. In Europe, the promising practices identified primarily focused on data and policy.

Example 8.1: In Ireland, a strong national data and guidance system guides local responses to housing issues. The National Housing Strategy for Disabled people 2022-2027 clearly aligns Irish policy and strategy with the UNCRPD in terms of accessibility and inclusion in the community. Other examples of policy and guidance include Rebuilding Ireland: Action Plan for Housing and Homelessness and Housing for All. Common to all of these is collaboration between Housing departments and other aspects of the services and support system around people with disabilities.

Example 8.2: In England, the National Planning and Policy Framework (NPPF) sets out the importance that council planning authorities must give to making decisions that create spaces that foster and not undermine the quality of life of citizens and community inclusion. The NPPF also sets out that most new housing developments over a certain size have to reserve a percentage of plots/houses as affordable houses, including, in some cases, as social housing.

Example 8.3: In Japan, the Housing Safety Net System ensures stable, adequate housing for the elderly, people with disabilities and others who require special assistance. This is achieved by using vacant housing stock and a public registry that owners of vacant rental properties can use to provide information about available properties that could be rented by people who require special assistance. Public authorities subsidise the costs of renovation and provide support to prevent/reduce housing cost overburden, for example, through tax credits. Finally, the programme offers matching services and support for people to move into the property.

Example 8.4: In the US, a scheme called Legacy Housing is used to support families who want to ensure housing for a relative with disabilities after their parents die. For example, the Ebles North Bay Housing coalition in California supports families who want to enable a person with disabilities to remain in the family home by donating the home to a nonprofit organisation on their death. They involve adult children in such decision-making to make sure that this is their preferred option, and are building a network of properties so that individuals can choose to move anywhere in California.

⁴⁴ <https://easpd.eu/resources-detail/models-of-promising-practices-on-independent-living-and-inclusion-in-the-community-for-people-with-significant-support-needs/>

Example 8.5: The use of tiny homes has been used in some places as a more general solution to emergency housing crises or to provide shelter for the homeless and those with mental health needs. For example, the West LA Veterans Centre in Santa Monica used Tiny homes to provide shelter for homeless veterans.⁴⁵ On Maui, Hawaii, after the wildfires in 2023, the government used Tiny homes to provide housing for people. Tiny homes are not necessarily the answer to all housing issues – land on which to put them is still needed. However, they can be made accessible relatively easily and can be designed around the person for a small proportion of the cost of a typical house. They can also be made permanent structures. However, like any housing development, attention needs to be paid to inclusive practices to ensure that any use of tiny homes does not become a campus development just for people with disabilities.

⁴⁵ <https://www.va.gov/greater-los-angeles-health-care/news-releases/first-tiny-shelters-delivered-to-va-west-la-campus-for-homeless-veterans/>



9. Incentivising community-based in-home support, not institutional options

For this area, which was identified as something that was needed to ensure that more people could benefit from community-based support, there were no examples identified to illustrate how this is being achieved for service providers. This does not mean that there are no examples, just that we were not able to identify them within the limitations of this work. However, examples were given of how benefits such as the Home Care Premium (HCP) and Caregiver Bonus in Italy and the Personal Assistance Budget in Flanders, Belgium, are being used to encourage families to continue to provide support for family members with disabilities in the family home.



10. Supporting a stable, skilled, motivated workforce

This final area of promising practice included a range of different approaches – including those focusing on additional ways to raise funding for NGOs, recruitment and retention strategies, and training. The concept and practice of Corporate Social Responsibility in place in Sweden was seen as having potential as a way of raising funds to financially support service providers.

In terms of attracting and retaining motivated staff, platforms such as Undivided in the US have helped support employers to retain workers who have disabilities or are carers of someone with a disability.

Example 10.1: In Flanders, a system of care ambassadors has been established to promote jobs in the care sector, with a particular focus on maximising the potential of informal caregivers or unemployed immigrants to become employed as care navigators to help fill gaps in culturally sensitive support for elderly people in underprivileged areas.

Finally, in a number of US states, there are initiatives focused on improving the recruitment and retention of direct support professionals, as well as the knowledge and skills with which they are equipped, in particular for those supporting people with developmental disabilities.

Example 10.2: In California, the Department of Developmental Disabilities has developed an internship program for Direct Support Professionals (DSPs) and is currently developing a Direct Support Professional University that will allow DSPs to be paid a higher level of pay on completion of each Tier of training.

Example 10.3: In North Carolina, the Department of Health and Human Services and the Community College System are launching an advanced Training Certificate for current DSPs or those interested in a career in the field. The pilot programme will be offered for free at three community colleges, and if successful, may expand to more colleges after the pilot.

Example 10.4: The National Alliance for Direct Support Professionals supports and recognises the work of DSPs and provides training programs that meet core competencies.

Example 10.5: The DSP Collaborative is currently coordinated by two Regional Centres working with service providers in their regions in California to provide information about jobs for DSPs and provide advice and resources for service providers, related to recruiting and retaining staff.

What is needed to make such approaches a reality for more people?

A key area where focus group participants felt change was needed was in the lack of political will to drive progress. Some also noted that the political narrative often still works against community-based services and NGOs striving to support the realisation of the UNCRPD. Incentives for institutional provision still exist in most countries (also commented on in Šiška and Beadle-Brown, 2022).⁴⁶ One participant highlighted that everyone needs to have a shared “vision and the dream that it will work”.

However, it was clear that even among service providers, there remains the view that institutional services are needed for some people with disabilities, that community living is not achievable for all and that people need to get or be made “ready” to live in the community. This “readiness” model needs to be replaced by a “support” model that says everyone can live and participate in all aspects of community life if given the right support to do so. However, some of the other barriers noted in this report, such as a lack of funding resulting in insufficient resources to meet the needs of those with higher or more complex support needs, make it difficult to demonstrate the support model and change attitudes.

More service providers providing community-based services are needed, offering a wider range of support for activities, participation and work, integrated in the community. There is especially a need for more providers to provide personal assistance to people in their own homes and a need for more respite services – in-home and in the community – to allow informal carers to take care of their own needs and those of other members of the family.

⁴⁶ Šiška, J., & Beadle-Brown, J. (2022). Progress on deinstitutionalisation and the development of community living for persons with disabilities in Europe: Are we nearly there? *Disability & Society*, 38(8), 1476-1495. <https://doi.org/10.1080/09687599.2022.2071676>

Collaboration and networking as a business model was proposed as an important way of identifying new sources of funding and support in the community. But also, collaboration was needed in the form of smaller agencies working together and sharing resources, especially in small towns in rural locations. It was noted in one focus group that Private Sector Social Responsibility in Sweden offered an example of a potential route to an additional source of funding.

Greater personalisation, especially of funding, is also needed – focus group participants particularly noted that “the money needs to follow the person.” But also noted that the ethos in most systems needs to change to start service provision with the individual and family – what do they need and how do they want that to be provided? Providing just what people need rather than fitting people into existing services is more efficient in the long run.

A greater focus is needed in policy and practice on the role of services, not just protecting and keeping people safe and physically well, but on quality of life much more broadly. Similarly, it was noted in some focus groups that service providers need to have a business model based on values and providing good quality. This needs to include even those providers that are independent/for-profit.

There is also still a need in many countries for housing and schools for people with disabilities to be planned much better in terms of location and integration. It is key that new housing, schools and leisure facilities are integrated and part of the general community, not located far from others and grouped in ghetto-like developments.

Staff need access to good training to help them work well within the true ethos of community living and to help them focus on the quality of life of the people they support and their families. Whilst in some countries being a support worker in services for people with disabilities is professionalised and qualifications are required; in most countries this is not the case. However, it is not just the availability of good training that is needed, but in many countries, the infrastructure

to ensure staff are able and motivated to attend such training and supported to implement their training in practice is missing. A way for providers to be able to release staff, pay them and support them to do training is needed in many countries.

One participant in the focus groups noted that “taking care of people costs money... It is supposed to cost money,” but the lack of sufficient investment in the care system was identified as an issue. A long-term view has been noted in the past as very important but often missing, especially in countries where health and social care policies and funding structures are determined by who is in power politically. If we invest early in 1) supporting families to have the skills and resources they need and 2) supporting children and young people to develop skills, reach their potential, build natural supports through community inclusion and be able to live as independently as possible, then we will reduce the need for more expensive and intensive services in the future, as well as improve the lives of individuals themselves.

Legislation was seen as important but only meaningful if translated into practice. Providers and families, in particular, need more examples to show people how to put models and approaches

into practice. There is also a need for more evaluation of implementation, checking whether the policy is really happening in practice in the lives of people with disabilities. Another aspect of this that was noted was the need to monitor more closely how funding is used and whether it is used to promote positive outcomes for those with disabilities. This requires a framework for measuring quality based on outcomes and experiences of those receiving services.

Finally, participants noted that there must be better communication and more proactive approaches to letting families know about what is available to support them and their family member with a disability. Families generally find information and services by chance or “through the grapevine” rather than through any official sources of information. This requires a change in attitudes and a different model for working, especially when resources are scarce. It requires creativity in meeting needs effectively, but as efficiently as possible with the resources available. There also needs to be more dialogue on the situation and experiences of people with disabilities themselves – both with the individuals and at higher levels – for example, in policy and decision-making circles.



► Conclusions

This small-scale study primarily sought to identify approaches that informal carers had reported had, or would have, been helpful to support more children with disabilities to remain living inclusive lives with their families and more adults with disabilities to live in the community, independent of, but connected to, their family, friends and other members of the community.

In comparison to previous work in this field, the types of barriers and issues faced by individuals and families were similar. However, by combining different sources of information and talking directly to family carers and service providers in different countries, we have been able to identify some additional areas on which to focus potential solutions.

The list of examples in each area of promising practice compiled in this report illustrates that it is possible to make good things happen even in countries where resources are limited. Consistent with the report by Šiška and Beadle-Brown (2020)⁴⁷ there were some good examples of progressive policies that are in line with the UNCRPD. However, there remain issues of implementation and a lack of data to demonstrate even progressive realisation of such policies in practice.

Good practice also often happens even without policies in place – sometimes it just takes an organisation or a small group of motivated people to decide to do something differently to make change happen. As such, individuals, families, communities, advocacy organisations and service providers do not have to wait for these things to be in place or whole systems to be aligned to do things that improve the lives, including the inclusion of people with disabilities and families. This report shows that much can be achieved by even one person or a small organisation doing something creative and working in collaboration with others – first steps are essential for change to happen incrementally.



The promising practices identified in the report occurred at different levels in the system, although many of those that were practice-based rather than policy-focused tended to be implemented by DPOs, individual service providers or were local government initiatives. Sometimes the same approach to support was provided by different levels and different types of organisations in different countries, even in different regions within the same country. Some of the promising practices identified would be relatively easy to implement – for example, providing information packs or clear online resources that are accurate, up-to-date, holistic and ideally a “one-stop-shop” for families to avoid the need for them to go searching for information. This does need one agency to take responsibility for leading a collaboration of other relevant agencies to produce, maintain and update information as needed.

Another relatively “simple” example would be for providers to change at least some of their clubs, facilities, activities and events into inclusive events rather than just for individuals with disabilities, by working together with another community organisation to run clubs together or inviting young people from schools to join in, etc. Whilst it can be hard for children and adults with disabilities to access the same facilities used

⁴⁷ <https://knowledgehub.easped.eu/local/dlotcms/resources.php?id=593>

by those without disabilities in some countries, usually it is easy for those without disabilities to attend events and activities in the same venues used by those with disabilities.

There are many other things that individual service providers or consortia of service providers can do in terms of being creative in how they provide services and lobbying for changes in funding systems and ways of organising services. For example, they can:

- ✓ Share resources with other disability providers (e.g. community-based housing stock; professionals and therapists, trainers) to support efficient use of resources and help each other to be effective and provide better support to more people in the community.
- ✓ Develop ways to use their existing funding differently and explain to funders and local governments how these changes meet local requirements but also take forward good practice and the UNCRPD. For example, if they are currently providing residential respite to children and families, how could they use this funding to provide a range of more regular in-home respite for families and more community-based activities?
- ✓ Collaborate with community clubs and organisations, schools, university and colleges, churches, hospitality providers, etc. to identify opportunities for a) individuals to participate in leisure, sport, hobbies, volunteering etc., alongside non-disabled peers; b) to build natural supports for people; c) to recruit volunteers, interns and paid staff; d) identify job opportunities for people; e) to identify potential housing stock, community buildings that could be used for integrated activity and other sources of funding.
- ✓ Work with researchers to document the current situation, changes made, and to collect data to evaluate impact and to share these findings with decision makers at all levels of the disability system.
- ✓ Work with the education system to support planning and skill development of young people as they move towards adulthood.

- ✓ Develop more social enterprises to help raise funds, provide people with opportunities to learn work-related skills and make connections with local businesses, clientele and other or future employers.
- ✓ Work with disabled people's organisations, local government/authorities responsible for service planning, to develop local action plans that offer solutions to the lack of community-based services over time.

However, for widespread change in the lived experience of people with disabilities and their families, there needs to be more systemic changes and leadership at national, regional and local government levels. This has to include a long-term perspective to planning and resourcing services and support. Mansell et al. (2007)⁴⁸, reiterated in Šiška and Beadle-Brown (2020)⁴⁹, highlighted the importance of taking a long-term view and set out a formula for the transition from institutional to community-based services that remains relevant today.

When service providers seek to develop and provide more community-based services to support families and adults with disabilities, national and local governments need to be open and supportive in finding solutions and making changes in the current system and processes to allow these proposals to at least be piloted and evaluated. In addition, new requests or applications from providers to set up segregated, institutional models of support should not be funded, neither from EU funds nor from State funds. Clear statements in terms of funding policies and guidance for service providers need to be available, with clear examples of the nature of services that will and will not be funded. Ensuring that over time more and more of local funding goes into person- and family-centred community-based services is critical to realising the UNCRPD.

⁴⁸ <https://bettercarenetwork.org/sites/default/files/Deinstitutionalisation-and-community-living---outcomes-and-costs--report-of-a-European-Study.pdf>

⁴⁹ <https://knowledgehub.easpd.eu/local/dlotcms/resources.php?id=593>

► Summary and recommendations

In order to improve the experiences of families, other informal carers and adults with disabilities themselves, changes are needed at different levels and across different sectors.

Overall, **stronger political will, investment, and governance** are needed to prioritise community-based care, fully implement the UNCRPD, and ensure legislation leads to real change through monitoring and evaluation. **People with disabilities and their families must be included in policymaking.** Carers need peer and social **support**, tailored help for diverse family needs, early training, and more in-home and community-based respite options. Families should have **clear, consistent information** and access to independent **navigation and advocacy** services, supported by better coordination

and an accessible information hub. **Planning** should start early and continue through life, supporting coordinated, person-centred services and informing local development. Services and schools must be **local and inclusive**, with well-trained staff and housing that enables independent living. **Funding should follow the person**, promoting personalised, flexible, and quality-of-life-focused support. People with disabilities require **lifelong healthcare, inclusive opportunities, and diverse employment and housing options.** A **skilled, fairly paid workforce** trained in person-centred practice is vital, as is **collaboration among agencies, innovation in service delivery**, and private sector engagement. Finally, **stronger EU data**, comparative research, and pilots of community-based models are needed to sustain progress and improve inclusion.



► Recommendations

Government/policymakers (local, national, EU)

- ✓ Clarify in law and policy that the complexity of a person's support needs can never be grounds for institutional or residential placement, and that all individuals are entitled to person-centred, community-based living arrangements. With the right support, everyone can and should, as a matter of right, live in a home of their own, chosen from the same living options available to people without disabilities at a similar age and stage of life.
- ✓ Make deinstitutionalisation a mainstream activity, not a project and the development of community-based support a priority. Back it up with long-term, protected funding. Enforce legislation and monitor outcomes to ensure UNCRPD is progressively realised.
- ✓ Shift resources from institutional care to personalised, community-based options, with funding that follows individual needs.
- ✓ Improve EU-wide data collection, setting clear definitions to be used and a minimum dataset to be returned, monitor quality of life outcomes, and collect data on implementation and quality of life outcomes of people over time, with a particular focus on innovative solutions to housing and support challenges.

Service planners & public authorities

- ✓ Introduce person-centred, all-age, whole-life planning to ensure smooth life transitions for individuals and their families, and to inform local service development at a system level.
- ✓ Ensure that schools, health care, and leisure services are locally available, accessible, and inclusive.
- ✓ Establish a single, regularly updated information hub, and expand independent navigation and advocacy services.
- ✓ Develop mechanisms to include the voices of people with disabilities and their families, and to ensure multi-agency and cross-sector collaboration.

Service providers & employers

- ✓ Provide early training for families, peer support groups, and gender- and culture-sensitive respite, leisure and social opportunities.
- ✓ Look for opportunities and innovative ways to expand the existing offer of services – find ways to offer personal assistance and bespoke support, even just to a few people with higher support needs. Document how you did it and evaluate the experiences and outcomes. Share with other providers.
- ✓ Ensure carers can reconcile work and family life with adequate leave, flexible employment, and pension protections.
- ✓ Improve pay, conditions, and training for support workers and other professionals to secure a skilled, stable workforce.
- ✓ Encourage joint ventures and resource sharing among providers and promote private-sector social responsibility to strengthen local capacity.

Disabled people's organisations, family support organisations and advocacy groups

- ✓ Work collaboratively with each other – be “stronger together” in advocacy.
 - ✓ Work collaboratively with stakeholders at all levels to ensure that the voices of people with disabilities and their families are consistently heard in decisions about services.
- ✓ Create opportunities to share positive experiences and lessons learnt from new initiatives so that development can continue over time.
 - ✓ Look for ways to expand independent navigation, advice and advocacy services (shared with planners/government above).
 - ✓ Encourage and support person-centred, whole-life planning that focuses on individuals—their hopes, dreams, and aspirations—rather than solely on the services they need.



► Annex 1: Methodology

This section outlines in more detail the key elements of the research undertaken.

Literature review

The starting point for the literature review was a list of 13 recent reports related to support for informal carers that had been collated by EASPD for inclusion in the review. The reports included are listed in Table 2 below.

As part of the literature review process, a set of core keywords and tailored Google search terms were used to identify relevant literature on informal care, family support, and disability-related policies. The aim was to explore current practices, policy gaps, and support systems for informal caregivers, especially those assisting individuals with disabilities. The following keywords guided the search and thematic focus: Informal care, Family, Good practices, Gaps, Policies, Disability, Services. We reviewed the search results, focusing on recent and reputable publications. Priority was given to

peer-reviewed journals, official reports, and sources from recognised organisations. From the results, we selected the most relevant materials, 30 sources, for closer review.

The authors extracted key information from each publication related to the guiding questions for the research. Extracted information included:

- ✓ How is informal care conceptualised within the disability system in different countries?
- ✓ Who provides and who receives informal care?
- ✓ What are the different approaches and types of support offered to informal carers?
- ✓ What challenges do informal carers face?
- ✓ What are the gaps in current research and practice?
- ✓ What recommendations have been made related to what is needed to improve the situation of informal carers?
- ✓ Any examples of good or promising practice identified and the evidence base for that practice.

Table 2: List of reports analysed for the literature review.

European Commission: Directorate-General for Employment, Social Affairs and Inclusion, *Long-term care report – Trends, challenges and opportunities in an ageing society. Volume II, Country profiles*, Publications Office, 2021.⁵⁰

Gender Equality Index 2019: Work-life balance - Informal care of older people, people with disabilities and long-term care services⁵¹.

European Institute of Women's Health, CLG A Lifetime of Caring Who Cares ISBN: 978-1-8380682-0-2.⁵²

⁵⁰ <https://data.europa.eu/doi/10.2767/183997>

⁵¹ <https://eige.europa.eu/publications-resources/toolkits-guides/gender-equality-index-2019-report/informal-care-older-people-people-disabilities-and-long-term-care-services>

⁵² <https://eurocarers.org/wp-content/uploads/2023/10/A-Lifetime-of-Caring-Who-Cares.pdf>

Eurocarers/IRCCS-INRCA (2021). Impact of the COVID-19 outbreak on informal carers across Europe – Final report. Brussels/Ancona.⁵³

Lambotte D., De Koker B., De Witte N., Simmons C., Yghemonos S., Champeix C., What informal carers say about long-term care services' accessibility, affordability, and quality – and how Care plans should respond.⁵⁴

European Commission (2024) NO ONE LEFT BEHIND! DIALOGUE ON THE FUTURE OF LONG-TERM CARE.⁵⁵

Eurocarers (2017). Why addressing the needs of informal carers is a crucial issue for Europe.⁵⁶

COFACE Families Europe (2017) WHO CARES? Study on the challenges and needs of family carers in Europe.⁵⁷

COFACE Families Europe (2024) Family carers in Europe today: State of play European Round Table.⁵⁸

European Economic and Social Committee (2024) Caregivers (Record of proceedings)⁵⁹

COFACE Families Europe (2018) long-term care: the family dimension key recommendations from COFACE Families Europe to shape long-term care systems for and with families.⁶⁰

Wellcare (2024) Report on analysis of legislation, policies, care frameworks and funding schemes.⁶¹

COFACE Families Europe (2024) The European Charter for Family Carers.⁶²

⁵³ <https://eurocarers.org/publications/impact-of-the-covid-19-outbreak-on-informal-carers-across-europe/>

⁵⁴ <https://www.euro.centre.org/downloads/detail/4596>

⁵⁵ https://employment-social-affairs.ec.europa.eu/document/download/41d72889-e608-4890-885c-9647a62c591d_en?filename=Flash%20report.pdf

⁵⁶ https://eurocarers.org/wp-content/uploads/2018/09/Eurocarers-Intro_final.pdfCOFACE

⁵⁷ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-Families-Europe_Study-Family-Carers.pdf

⁵⁸ https://coface-eu.org/wp-content/uploads/2024/12/RTFamilyCarers_KeyFindings.pdf

⁵⁹ <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/caregivers#downloads>

⁶⁰ https://coface-eu.org/wp-content/uploads/2021/12/COFACE-paper_Families-dimension_v4.pdf

⁶¹ <https://wellcare-project.eu/wp-content/uploads/2024/10/WellCare-D4.1.pdf>

⁶² <https://coface-eu.org/european-charter-for-family-carers/>

Stakeholder consultation

An invitation to participate in focus groups was distributed through EASPD networks (including COFACE Families Europe and Eurofam), Inclusion Europe, and the authors' own contacts within European Disability Expert networks. The invitation contained a link where potential participants could provide consent to be contacted by EASPD or the authors. Participants were invited either to take part in a focus group and/or to review the list of promising practices and were asked to indicate which option(s) they were willing to join. In total, eighteen people returned the consent form: four agreed only to participate in a focus group, eight agreed only to review the promising practices, and six agreed to do both.

Focus group procedure

Two focus groups were organised with informal carers who also knew service systems in their respective countries. Altogether, six people attended the informal carer groups, bringing together knowledge from at least 7 European countries, some having experienced being an informal carer in more than one country. One participant also had more general knowledge of service systems across Europe. Five representatives from 4 different service providers in Italy and Slovakia participated in the focus groups with service providers. The questions used to guide the focus groups are provided in Table 3 below.

All focus groups were conducted in English and facilitated by two researchers: one led the discussion while the other took detailed notes. To ensure accuracy, the sessions were also recorded and later checked against the notes. All focus groups lasted approximately 90 minutes.

Analysis

The detailed notes from each focus group were reviewed by one author. Key segments were coded for each focus group separately, and then the codes were grouped into broader themes.

Informal carers' focus groups were analysed first, and coding focused on the views and experiences of informal carers in different countries related to each of the overarching guiding research questions (e.g. challenges met, type and usefulness of support provided, what else should have been helpful). Analysis of Service provider focus groups, focused initially on the type of support currently provided to informal carers, what other types of support were needed to respond to the challenges experienced by families and individuals with disabilities and what was needed to ensure more people experienced good practice and outcomes.

Due to the qualitative nature of the research and the small number of participants, comparisons across groups or countries were not explored – themes were identified across all focus groups.

Table 3: Questions used to guide the focus groups

Informal Carers	Service Providers
What are some of the major challenges or difficulties experienced by children with disabilities and their families in your experience?	What are some of the major challenges or difficulties experienced by children with disabilities and their families in your experience?
What puts children with disabilities at risk of being taken into care/institutionalised?	In particular, what puts children with disabilities at risk of being taken into care/institutionalised?

Informal Carers	Service Providers
What has helped you or other families you know?	What in your practice or the practice of other service providers you know has contributed to supporting families in preventing the need to take children to formal care?
What would have helped you or other families you know?	What else could disability services providers do to help families and informal carers, and support children living at home and being included in family and community life? Which type of disability services?
What contact have you had with disability service providers? Was this helpful? How could it have been more helpful?	In your experience, what are some of the major barriers to adults with disabilities being able to live in a home they choose that is similar to those without disabilities, live on their own or with people they choose, participate fully in their community?
What else could disability services providers do to help families and informal carers and support children living at home and being included in family and community life?	What was needed to establish the service or type of support (choice, participation) and maintain it over time?
What are some of the major barriers in your experience to adults with disabilities being able to live in a home they choose that is like those without disabilities, live on their own or with people they choose, and participate fully in their community?	What would help this to happen more often and for more service providers?
What in your experience has helped adults with disabilities to live and participate in the community, with support as needed?	
What would help this to happen more often and for more people?	
What support do families need for this to happen?	
What role do or could disability service providers have in making this happen?	
What types of services have been helpful for you, your adult family member or someone else you know?	
How could services have been more helpful?	

Development of promising practices

Further analysis of the themes from the focus group was conducted to identify examples of promising practice. This was combined with findings from the literature review. We then thematically organised the findings into Areas of Promising Practice. Ten areas of Promising Practice were identified.

We then identified a range of concrete examples in each area of promising practice from three sources:

- ✓ From the focus group participants.
- ✓ From our own knowledge of practice in different countries and from previous EASPD and other agency reports
- ✓ Through a Google search, looking for examples of practice in each area of promising practice. The aim of the search was not to be comprehensive but rather to identify one or more examples that could be used to illustrate the promising practices and give service providers, policy makers and families ideas of what was possible to achieve.

We then sent the list of areas of promising practice and a selection of the examples we had already identified for each area to the 14 stakeholders who had agreed to review the promising practices. Responses were gained from five people – three service providers working in Italy, 1 service provider working in Belgium and 1 person working in an international organisation who was able to provide examples from different countries.

In addition to gathering more examples, we asked participants whether we had missed any areas of promising practice or whether any areas should not be included. No one suggested the addition or removal of promising practices, but some did mention things that were needed to ensure implementation of promising practices, and these have been included in the section above. One person noted that many of the areas of promising practices overlap, and how changes at the system level could make many of these a reality for many more people with a disability and their families.



► Annex 2: Examples of Promising Practices

Co-ordinated [early] support services (from birth or diagnosis) providing information, navigation, training, benefits advice and service coordination

- ✓ In Switzerland, in the first couple of days after birth, even when disability is not expected, families receive an information pack about available services and who to contact for help (focus group).
- ✓ In Slovakia, there is an early intervention and advice centre for families, based at a school. Another example is a community centre where, if a parent has a mental health need, the child is proactively assessed. Similarly, if a child is referred for an issue, the parent also meets with an expert to see if they have any needs (focus group).
- ✓ Also in Slovakia, UNICEF, the European Commission, and the Ministry of Labour, Social Affairs and Family collaborated to produce a series of technical guides (noted as aspirational rather than regulatory) for the Ministry itself, Offices of Labour, Social Affairs and Family, and Centres for Children and Families. These guides aim to support the inclusion of children with disabilities in the context of deinstitutionalisation and what is referred to as 'substitute' care. The third guide focuses particularly on the role of case management.⁶³
- ✓ In England, Children's Health and Well-being Navigators are identified for young children early in life, especially if any developmental or health concerns emerge.⁶⁴ The Neurodiversity Profiling Tool⁶⁵, developed in Portsmouth

and piloted in other English counties, helps to identify and map children's needs from an early stage through school. It consolidates information in one place, provides support strategies for families, and signposts people to appropriate services.

- ✓ In Greece (as in other countries), every family receives the National Child Health Booklet. Unlike in most other countries, this booklet continues to be used not only by health professionals and families but also by early intervention staff and schools, facilitating communication and referrals when developmental concerns arise. It provides families with information about what to expect at different stages of development, when to seek further support, and what services are available. Primary care providers also receive guidance on how to use the booklet.⁶⁶
- ✓ In Bulgaria, as part of the Child Guarantee pilot and the implementation of the National Action Plan, the early identification and early childhood intervention services system has been expanded. One example is the Karin Dom Foundation in Varna, which provides early intervention services to prevent the abandonment of children with disabilities. The service offers a wide range of therapies for children, as well as support and training for families, all under one program.⁶⁷
- ✓ In Portugal, the National System of Early Childhood Intervention is well established. The NGO CECD Mira Sintra operates a Team around the child approach - a multidisciplinary team of qualified professionals from different sectors, including health, education, social work, and psychology. Together, they help families access services and benefits, while supporting children in developing skills within

⁶³ https://www.unicef.org/ecg/media/40121/file/TSL_Guidance_3_16-04-25v2.pdf

⁶⁴ <https://www.wealdpcn.co.uk/childrens-health-and-wellbeing>

⁶⁵ <https://portsmouthlocaloffer.org/information/the-neurodiversity-nd-profiling-tool/>

⁶⁶ <https://www.moh.gov.gr/articles/health/dieythynsh-prwtobathmias-frontidas-ygeias/draseis-kai-programmata-agwghs-ygeias/oikogeneiakos-programmatismos/4392-bibliario-ygeias-paidioy?utm>

⁶⁷ <https://karindom.org/en/early-intervention/>

their natural environments (home, day care, kindergarten) through daily activities and routines. Within each team, one professional is designated as the case coordinator.^{68 69}

- ✓ In Italy, focus groups highlighted the Life Project⁷⁰, through which training is provided for families soon after diagnosis to help them envision a positive future and shift attitudes and expectations. The Foundation Paideia provides additional training and support, operating with a 'Team around the child' approach. A multidisciplinary team—including psychologists, psychomotor therapists, speech therapists, social workers, music therapists, and occupational therapists—works with the family to ensure adequate and appropriate support.⁷¹
- ✓ The Italian organisation Anffas⁷² provides substantial information for individuals and families on its website and offers training both online and in person.
- ✓ In Italy, several tools and technologies are also used as 'digital navigators.' Some focus specifically on supporting families of autistic children, such as the Super Platform⁷³ and Piattaforma PIA⁷⁴. Others, like AreAto.org, provide accessible information through a portal mapping services, rights, and opportunities for families with disabilities, acting as a social navigator and empowering families with clear guidance.⁷⁵ In Oregon, US, the State provides a Family Caregiver Support Program that assists family members and friends providing care beyond the normal parental role. Support includes information,

help with accessing services, legal assistance, advice, counselling, and respite care. Online resources include a Family Caregiver Handbook and Caregiving Guides.⁷⁶

- ✓ In California, the Community Navigator Program works in partnership with the Family Resource Centres Network of California to provide one-to-one support for individuals and families in accessing and using services.⁷⁷ A related service, Coordinated Family Support, assists adults with developmental disabilities who live in the family home.⁷⁸
- ✓ In Australia, guidance exists for teachers, educators, and service providers to help them reflect on and improve their interactions, and to collaborate with families to promote children's learning and development.⁷⁹
- ✓ In Finland, Omaperhe provides a website resource for families that covers many topics, including guidance for those caring for a seriously ill or disabled child.⁸⁰

All-age, whole-life, person-centred planning

- ✓ In the UK⁸¹ and in Ireland⁸² person-centred planning is a national policy for people with intellectual disabilities. There are many sources of training on person-centred planning and numerous online resources available. However, there are often concerns about whether having a plan actually leads to a better quality of life.⁸³

⁶⁸ https://ecigreece.eu/wp-content/uploads/2024/04/D4.5-EU-Inspiring-Practices_EN_layout.pdf

⁶⁹ www.cecd.pt

⁷⁰ https://en.ilssole24ore.com/art/school-and-work-project-life-disability-AFecNbXD?refresh_ce=1

⁷¹ https://ecigreece.eu/wp-content/uploads/2024/04/D4.5-EU-Inspiring-Practices_EN_layout.pdf

⁷² <https://www.anffas.net/>

⁷³ https://www.sinapsi.unina.it/sistema_unitario_piattaforma_educativa_riabilitativa

⁷⁴ <https://www.oslcn.it/assistenza-territoriale/salute-mentale/servizio-di-psicologia-e-psicopatologia-dello-sviluppo/piattaforma-pia>

⁷⁵ <https://www.oreato.org/info-disabilita/>

⁷⁶ https://adrcforegon.org/consumersite/explore/more_options/caregiver_supports.php

⁷⁷ <https://www.dds.ca.gov/rc/disparities/community-navigator-program/>

⁷⁸ <https://www.dds.ca.gov/services/coordinated-family-support-service/>

⁷⁹ <https://www.edresearch.edu.au/sites/default/files/2022-11/family-engagement-disability-guide-ecec-aa.pdf>

⁸⁰ <https://omaperhe.fi/en/children-1-6-years/growth-and-development/support-for-childrens-rehabilitation>

⁸¹ Valuing People White Paper (2001).

⁸² https://nda.ie/uploads/publications/Guidelines-on-Person-Centred-Planning_plain-english.pdf

⁸³ <https://www.ndti.org.uk/resources/publication/introduction-to-person-centred-planning-tools>

- ✓ In Italy, policymakers are developing a policy framework to promote person-centred, strengths-based, lifelong planning (progetto di vita – Law 328/2000, Art. 14)⁸⁴ ⁸⁵ The Individual Life Project establishes the right to a co-produced, personalised plan with family and services.
- ✓ Law 112/2016 “Dopo di Noi” (After Us) funds supported living and life projects for situations where families can no longer provide support.
- ✓ Decree 182/2020 introduced the ICF-based Individual Education Plan (PEI), which connects education plans to broader life projects.
- ✓ In the Netherlands, the Een Rijk Leven (A Rich, Inclusive Life) project⁸⁶ supports people with disabilities and complex support needs to lead self-determined lives within their communities. Participants co-design their lives with family, community members, and professional supporters. Assistance is provided via Personal Budgets (PGBs), allowing for individualised care arrangements.
- ✓ In Sweden, there are also positive examples of person-centred planning for people with intellectual disabilities.⁸⁷

Social and emotional support and connections – for parents, siblings and the whole family

- ✓ In Italy, the Fondazione Paideia⁸⁸ provides empowerment and connection support to combat isolation and promote self-help/solution finding. It organises peer group

discussions for mothers and fathers separately, recognising their different needs. Informal support for families is offered during activities for children. A Carer Stress Group (with mixed ages of children) benefits both families of older children, who can see how far they have come, and families of younger children, who gain hope for the future. Additional initiatives include peer support for siblings and combined summer camps for children and their siblings.

- ✓ In Ohio, US, the Bring Fathers Forward Program provides specific support for fathers of children with disabilities.⁸⁹
- ✓ In Bulgaria, Karin Dom offers family-mediated intervention, where groups of parents and children work together, supported by a professional.⁹⁰
- ✓ In Slovakia, the Platform of Families of Children with Disabilities: #ParentsToParents is a civic association operating nationwide. It was initially established as an informal parental initiative in response to the need to improve conditions for children with all kinds of disabilities and their families.⁹¹
- ✓ In Greece, the Greek Parents Association for the Supported Living of People with Intellectual Disabilities (PETAGMA) provides emotional well-being support to families and advice to help them prepare for the transition to supported living. They also run a sibling support group and offer information and education on disability issues.⁹²
- ✓ The ECDUR Project (Emergency Early Childhood Development Support for Ukrainian Refugees), implemented by UNICEF and EASPD between July 2022 and December

⁸⁴ Perego C, Oberti I, Pavesi AS. «Progetto di Vita» and Universal Design for Persons with Disabilities. *Stud Health Technol Inform.* 2022 Sep 2;297:201-208. doi: 10.3233/SHTI220840. PMID: 36073396.

⁸⁵ https://en.ilsole24ore.com/art/school-and-work-project-life-disability-AFecNbXD?refresh_ce=1

⁸⁶ https://easpd.eu/fileadmin/user_upload/Projects/ICALL/ICALL_D2.2_Collection_of_promising_practices_of_inclusive_communities_EN.pdf

⁸⁷ <https://sjdr.se/articles/10.16993/sjdr.1147>

⁸⁸ <https://fondazionepaideia.it/>

⁸⁹ <https://dodd.ohio.gov/your-family/advocacy/bff>

⁹⁰ <https://karindom.org/en/therapeutic-groups-for-children-and-parents/> <https://www.eenet.org.uk/enabling-education-review/enabling-education-review-8/eer-8/family-mediated-intervention-to-support-inclusion-in-bulgaria>

⁹¹ More: <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/platform-of-families-of-children-with-disabilitiesparentstoparents/>

⁹² <https://petagma.gr/ypostirixi-oikogeneiwn/>

2023 in Poland, Slovakia, Romania, Moldova, and Bulgaria, aimed to provide early support to refugee children at risk of developmental delays while strengthening national Early Childhood Intervention (ECI) systems. A key innovation was the creation of peer support for families by training over 500 Ukrainian refugee parents as Peer Support Group Facilitators. Drawing on their shared experiences of displacement and parenthood, these facilitators led small group sessions, provided individual guidance, organised community activities, and linked families with professional services. This approach fostered trust, empowerment, and solidarity among families while easing pressure on formal services, ultimately reaching more than 20,000 children and their caregivers. Recognised with a Zero Project 2024 Award, ECDUR not only offered immediate relief but also produced policy recommendations, national assessments, and advocacy initiatives to strengthen family-centred ECI systems in Europe, leaving behind a model that can be replicated in other emergency contexts.⁹³

- ✓ In the US, the Sibling Support Project⁹⁴ provides support and training to siblings of children with disabilities.
- ✓ In Australia, Siblings Australia Inc.⁹⁵ provides substantial support for siblings of people with disabilities, as well as training for professionals who work with them.
- ✓ In Ireland, Springboard is a Family Support Project that operates in several cities across the country, with different organisations responsible for management. For example, the Tusla Child and Family Agency runs the project in Cork.⁹⁶ Springboard provides training, counselling, and support groups for families, working across all children but focusing particularly on those at risk, such as children facing homelessness or exclusion.

Personalised, flexible, creative funding and assistance/support

- ✓ In many countries in Europe, personal budgets and personal assistance services are now available, at least as pilot projects (from focus groups and research).⁹⁷
- ✓ In Finland, personal assistance is a right for people with severe disabilities under the Disability Act. The goal is to support independent living by assisting with everyday tasks and enabling participation in society. There are three options for receiving personal assistance, offering more flexibility than is often seen in other countries.⁹⁸ Families can also access personal assistance for their child. In addition, there is a carer's allowance for families of children with disabilities.⁹⁹
- ✓ In Scotland, the Enable Personal Assistant mode¹⁰⁰ was developed by Enable in response to the Self-directed Support (Scotland) Act 2013. It has been tested and shown to be scalable and transferable to other people and settings. The model is designed to support direct payment of a person's social care budget, giving them full control over how it is spent without the complications that typically arise from becoming an employer. Small bespoke teams are chosen by the individual and contracted directly with them.
- ✓ In Salzburg, Austria, a flexible, needs-based personal budget pilot was launched in 2017, allowing truly tailored assistance and funding.¹⁰¹ Lebenshilfe also runs a personal assistance project.¹⁰²

⁹⁷ <https://knowledgehub.easped.eu/local/dlotcms/resources.php?id=593>

⁹⁸ <https://www.esn-eu.org/practices/personal-assistance-finland-legislation-implementation-statistics-and-challenges-future>

⁹⁹ <https://omaperhe.fi/en/children-1-6-years/growth-and-development/support-for-childrens-rehabilitation>

¹⁰⁰ <https://easped.eu/resources/innovation-awards/detail-innovation-awards/enable-personal-assistant-pa-model/>

¹⁰¹ <https://www.unicproject.eu/projectnews/personal-budgets-and-personal-assistance-success-and-challenges/>

¹⁰² <https://persoenliche-assistenz-salzburg.at/>

⁹³ <https://easped.eu/news-detail/family-consultants-to-support-children-with-disabilities-who-fled-the-war-in-ukraine/>

⁹⁴ <https://siblingssupport.org/>

⁹⁵ <https://siblingsaustralia.org.au/>

⁹⁶ https://www.tusla.ie/uploads/content/Tusla_-_Springboard_Leaflet.pdf

- ✓ In the United States, the platform Undivided¹⁰³ provides support to employers of informal carers of children with disabilities, helping families keep their jobs while enabling employers to retain a valuable workforce.
- ✓ In Italy, Law 104/1992 protects the rights of persons with disabilities and their families. It provides a range of benefits, including paid leave and time off work for workers with disabilities or their family carers, tax breaks for the purchase of goods and services (e.g., cars and aids), and priority choice of workplace.

In-home respite, leisure, sport and opportunities for participation, friendship and inclusion

- ✓ Special Olympics Unified Sport was identified as very helpful for promoting participation in sport and more generally in society. One example is volleyball, where teams must include three people with and three without intellectual disabilities. Just as important as the sport itself is the opportunity for all players to share a beer after the game or practice. The common focus on sport equalises differences between players and fosters social connection.
- ✓ In Spain, a young man, with the support of his sister and community connections, works as a football trainer for children.
- ✓ In Austria, individuals with disabilities are included in educational programs as Sports Management Assistants. Evaluations of their experiences, as well as feedback from the sports venues and events that employed them, have been overall positive.¹⁰⁴
- ✓ In Finland, the Tukena Foundation (formerly KVPS) offers the Family Relief Service (FRS), a short-term care service delivered in the family's home. A family support worker assists family members and siblings of a person with a disability. This service gives parents and carers a moment of rest and empowers them to strengthen their independence and voice.¹⁰⁵

¹⁰³ <https://www.undivided.io/for-employers/>

¹⁰⁴ <https://pmc.ncbi.nlm.nih.gov/articles/PMC11968761/>

¹⁰⁵ <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/same-model-1/>

- ✓ Also in Finland, SavasRock¹⁰⁶ is an inclusive rock festival aimed at raising awareness of intellectual disabilities, breaking barriers, and removing prejudices. Moving away from events exclusively for persons with disabilities it brings everyone together to enjoy music in a friendly atmosphere with top artists, restaurant services, alcohol, and street food. Accessibility is integrated throughout: Picture Communication Symbols (PCS) illustrate the environment, a quiet space is provided for sensory regulation, and sign language interpretation of music is available.
- ✓ In Greece, Help at Home¹⁰⁷ provides home support services to elderly persons and persons with disabilities who live alone and need personal care, health support, and assistance with daily activities. This enables them to remain in their own homes and avoid institutionalisation and exclusion.
- ✓ Supereroi Printre Noi's "Art is Everyone's Gift"¹⁰⁸ project in Greece raises awareness, fosters empathy, and promotes equal participation for neurodiverse persons and persons with disabilities, particularly those with intellectual disabilities, by organising fully accessible and inclusive events. These events include adapted concerts, theatre performances, literature clubs, exhibitions, and film screenings tailored to the needs of people with complex disabilities. The events amplify the voices of persons with disabilities, combat stereotypes, and encourage social understanding.

¹⁰⁶ <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/savas-rock/>

¹⁰⁷ https://easpd.eu/fileadmin/user_upload/Factsheet_3_-_Help_at_Home_-_EN_-_Web.pdf

¹⁰⁸ <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/art-is-everyones-gift/>

- ✓ The Nevronas FESTivalin Athens¹⁰⁹ is a Festival of Inclusive Performing Arts and Artistic Interaction, held annually at the Technopolis of the Municipality of Athens. It promotes accessibility and inclusion in the arts, empowering both professional and amateur artists with and without disabilities. Its Inclusive Volunteering Programme gives volunteers with and without disabilities the opportunity to develop skills, learn from the festival, and engage in social interactions. Volunteers receive specialised training on disability, neurodiversity, and inclusion, with tailored sessions provided as needed.
- ✓ In Bosnia and Herzegovina, the ALL INCLUSIVE Project,¹¹⁰ centred on the performing arts, promotes the social inclusion of people with disabilities and other marginalised groups, empowering them to actively shape and participate in cultural activities. Through collaborative workshops led by artists with and without disabilities and co-produced with and for disadvantaged communities, participants develop creative and professional skills. The project culminates in a multidisciplinary theatre production that amplifies the voices of marginalised people and provides a platform for inclusive cultural expression and cross-community cooperation, and advocacy.
- ✓ In Italy, Estate Paideia¹¹¹ invites families (including grandparents and siblings) to spend a week together on summer vacation with other families and volunteers. Activities are organised for adults and children, allowing flexible participation. Families can focus on the child with disabilities while also giving attention to siblings, who gain autonomy, feel involved, and enjoy age-appropriate experiences in a supportive environment.
- ✓ The Paideia Center Workshops in Italy provide recreational and creative activities, both inclusive and disability-specific, where children can express themselves, learn, and grow in a safe and welcoming environment.
- ✓ Italy also offers Inclusive Sports Activities, including adapted sports, outdoor experiences, and the Tutti in Sella! project with accessible bicycles. These initiatives promote autonomy, fun, and friendship, while creating opportunities for families to rediscover well-being and shared joy, creating spaces where every child feels valued and every family feels supported.
- ✓ In Belgium (Brussels), LASSO¹¹² promotes inclusive art projects that foster participation and creativity for all.

Services that support the development of skills and transition to adulthood - shaping up independence for both families and the person with disabilities

- ✓ In Italy, opportunities for young people with disabilities to attend camps or shorter overnight trips provide them with a chance to gain independence from their families. For example, Fondazione Paideia¹¹³ offers immersive residential weekends (Autonomy and Future – “Piani di Volo”) where children and adolescents with disabilities can practice daily living skills in a safe, realistic setting. Participants engage in routines, farm activities, and experiential programmes (e.g., educational circus, mindfulness, cooperative play) to strengthen independence, confidence, and social skills.

¹⁰⁹ <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/nevronas-festival-inclusive-volunteering-programme/>

¹¹⁰ <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/all-inclusive-performing-arts-for-diversity-and-social-inclusion/>

¹¹¹ https://fondazionepaideia.it/cosa-facciamo/estate-paideia/?_gl=1*13qier*_up*MQ..*_ga*MjQ4NTMzODE0LjE3NTYyMTc5OTE.*_ga_TYS61BM7VQ*_czE3NTYyMTc5OTAKbzEkZzAkdDE3NTYyMTc5OTgkajUyJGwwwJGgxNDI5NjIzMDYz

¹¹² <https://lasso.be/en/projects>

¹¹³ <https://fondazionepaideia.it/>

- ✓ The Fattoria Sociale Paideia (in Baldissero Torinese and Caramagna Piemonte) offers opportunities for young people to take part in agricultural activities, workshops, and animal care, helping them develop practical, social, and professional skills in an inclusive environment. These programmes provide concrete pathways for autonomy, work experience, and personal growth, supporting young people and their families in preparing for adulthood.
- ✓ In Flanders, the concept of shared care was seen as a valuable and supportive arrangement, allowing young adults to spend three days a week in a small group living setting and the remaining four days at home with their families (example from focus group).
- ✓ The Inclusive Path Project¹¹⁴ is a new initiative launched in 2025 that aims to improve the transition of individuals with intellectual and developmental disabilities (IDDs) to post-secondary education (PSE) or Adult Learning & Education (ALE). It does so by training teachers and staff in Secondary Education (SE) and PSE, and by empowering families and children with IDDs. The project also seeks to develop interactive, game-like resources to support young people and their families in making decisions related to the transition to adulthood.
- ✓ In Belgium, the Brake-Out Project¹¹⁵ helps young people identify their skills and plan for their future, supporting their transition to adulthood.

¹¹⁴ <https://easpd.eu/project-detail/inclusive-path/>

¹¹⁵ <https://konekt.be/en/brake-out-homepage/3-year-programme-of-brake-out>

Progressive and customised employment support for people with disabilities

- ✓ In Finland, Vocational Rehabilitation services support people in getting and keeping jobs, for example, through job coaching.¹¹⁶
- ✓ In Greece, Margarita¹¹⁷ offers a preparatory programme to train and prepare persons with intellectual disabilities for independent living. The goal is either to transition to community-based living, to their own apartment, or to continue living with their families while avoiding institutionalisation later in life. The programme includes vocational training and prepares participants for inclusion in the labour market. Although it is based more on a readiness model than on a rights-and-support model of community living, it demonstrates how people with intellectual disabilities can be supported to prepare for employment in the open labour market.
- ✓ In France, the Support Apprenticeship system by LADAPT association¹¹⁸ is designed to help people with disabilities transition to work through apprenticeship contracts. Its unique feature is its holistic approach: it considers the entire ecosystem surrounding the person, making it possible to support not only the apprentice with administrative procedures but also the employer and training centre.
- ✓ In Germany, Zukunft trotz Handicap¹¹⁹ provides opportunities for individuals with disabilities—many of whom have previously worked only in sheltered workshops—to gain training and experience in two new qualifications: the daycare training programme, preparing individuals for careers in childcare, and the gastronomy training programme, preparing participants for roles in hotels, catering, and housekeeping. The programmes include internships alongside theoretical components.

¹¹⁶ <https://www.kela.fi/vocational-rehabilitation-for-young-persons>

¹¹⁷ https://easpd.eu/fileadmin/user_upload/Factsheet_7_-_Margarita_-_EN_-_Web.pdf

¹¹⁸ <https://easpd.eu/news-detail/support-apprenticeship-system-by-ladapt/>

¹¹⁹ <https://easpd.eu/resources/innovation-awards/detail-innovation-awards/zukunft-trotz-handicap-ev-professional-development-employment/>

Creative solutions for housing in the community

- ✓ In Brussels, Hubbie offers voluntary work support for people with disabilities and is a member of Werkburo (werkburo.be). Werkburo envisions a world in which all people with disabilities have a job that allows them to make the most of their skills, live with dignity, and receive sufficient guidance to pursue a meaningful personal journey. To achieve this, Werkburo focuses on all stages of the participation ladder, especially for those furthest removed from the labour market. It guides adults through individual programs toward work-related activities in the regular labour market, ensuring coordinated access and efficient use of available resources. While an income through work is the goal, it is not considered a prerequisite for supporting a person with a disability in finding a role in the world of work. Hubbie currently supports around 40 clients who have found voluntary jobs through its mediation.
- ✓ In Germany, as one result of its training program, Zukunft trotz Handicap¹²⁰ opened an Inclusion Coffee Shop in May 2023. Achieving sustainable employment placements subject to social insurance contributions requires tailored support for young adults entering the open labour market. The program collaborates closely with participants to identify suitable organisations and companies based on their aptitudes and skills, easing their integration into the workforce. Partnerships with stakeholders have been built to support initial cohorts. Programs provide practical instruction tailored to individual needs and interests, reaching underserved social groups who lack traditional training opportunities. Corporate cooperation requires persuasive efforts, but the program's extensive network ensures that individuals from its target demographic fill all available slots.

- ✓ In Ireland, there is strong national data and guidance related to the housing situation of people with disabilities and mental health needs, with a particular focus on systemic responses.¹²¹ The National Housing Strategy for Disabled People 2022–2027 clearly aligns Irish policy and strategy with the UNCRPD, emphasising accessibility and inclusion in the community. Other examples of housing-related policy and guidance include Rebuilding Ireland: Action Plan for Housing and Homelessness and Housing for All. A central theme across these policy documents is collaboration between housing departments and other parts of the service and support system for people with disabilities.
- ✓ In the United States, the Legacy Housing scheme is used. One example is Ebles North Bay Housing Coalition in California,¹²² which works with people who want to enable a person with disabilities to remain in the family home once parents have passed away, by donating it to a nonprofit. Adult children are involved in decision-making to ensure it reflects their preferences. The initiative is also building a network of properties so that people can choose to move anywhere in California.
- ✓ In England, the National Planning Policy Framework (NPPF) highlights the importance of ensuring council planning authorities make decisions that create spaces which foster, rather than undermine, citizens' quality of life and community cohesion. The NPPF also requires that most new housing developments over a certain size reserve a percentage of units as affordable housing, sometimes including social housing.¹²³

¹²⁰ <https://easped.eu/resources/innovation-awards/detail-innovation-awards/zukunft-trotz-handicap-ev-professional-development-employment/>

¹²¹ https://www.disability-federation.ie/assets/files/pdf/the_right_home_the_housing_needs_of_people_with_disabilities.pdf

¹²² <https://www.specialneedsalliance.org/blog/getting-creative-models-for-filling-the-housing-gap/>

¹²³ <https://www.dlapiper.com/en/insights/publications/real-estate-gazette/real-estate-gazette-living-capital/11-uk-englands-affordable-housing-regime>



- ✓ The use of tiny homes has become increasingly popular in various contexts to address housing crises—for example, for people experiencing homelessness,¹²⁴ those with mental health needs,¹²⁵ or in disaster recovery situations such as the fires in Maui.¹²⁶ Tiny homes can be made accessible relatively easily and designed around individual needs, and they can also serve as permanent structures. However, as with any housing

¹²⁴ <https://www.va.gov/greater-los-angeles-health-care/news-releases/first-tiny-shelters-delivered-to-va-west-la-campus-for-homeless-veterans/>

¹²⁵ Wilson AB, Villodas ML, Mahadevan T, Bosman E, Swaine J, Gilmore JH, Bowman L, Money-Garman A. Tiny homes-big movement: building a permanent and affordable housing option for people with severe mental illness. *Front Public Health*. 2025 Jun 17;13:1516751. doi: 10.3389/fpubh.2025.1516751. PMID: 40600160; PMCID: PMC12209311.

¹²⁶ <https://www.mauinews.com/news/local-news/2025/07/temporary-housing-projects-grow-with-lahaina-wildfire-survivors/>

development, inclusive practices must be ensured so that tiny homes do not become segregated 'campus' housing exclusively for people with disabilities.

- ✓ In Japan, the Housing Safety Net System ensures stable, adequate housing for the elderly, people with disabilities, and others requiring special assistance. It does this by utilising vacant housing stock and maintaining a public registry where owners of empty rental properties can list them as available for people who require special assistance. Public authorities subsidise renovation costs and help prevent or reduce housing cost overburden, for example, through tax credits. The program also offers matching services and move-in support (2021 OECD QuASH).¹²⁷

¹²⁷ https://www.oecd.org/content/dam/oecd/en/publications/reports/2021/09/a-crisis-on-the-horizon_f5739419/306e6993-en.pdf

Incentivising community-based in-home support, not institutional options

- ✓ In Italy, incentives for community-based support are mainly targeted at individuals and families rather than private service providers. These measures aim to help people remain at home and receive care in the community instead of in institutions. They include the Home Care Premium (HCP)¹²⁸ and the INPS Caregiver Bonus, which supports family members caring for people with severe disabilities. Managed regionally, amounts and conditions vary by region. For example, the Piedmont Region¹²⁹ offers a Monthly Allowance for Home Care of around €600 per month for people with disabilities. This allowance can be used to cover the cost of family caregivers or accredited services, based on individual care plans.
- ✓ In Flanders, parents or family members (up to the second degree) can set up Parent Initiatives, which operate as non-profit organisations or foundations. These initiatives organise care and support for small groups (up to a maximum of 15 people with disabilities). Funding is only received through the Personal Budget (PVB) in cash, while the Personal Assistance Budget (PAB) can be used for up to 155 days or nights per year. Parents must collaborate, pooling budgets to support all participants, including people without a PVB.

¹²⁸ https://www.inps.it/it/it/dettaglio-scheda_it.schede-servizio-strumento.schede-servizi_hcp-assistenza-domiciliare-per-persone-non-autosufficienti-home-care-premium--50014_hcp-assistenza-domiciliare-per-persone-non-autosufficienti-home-care-premium-domanda-e-gestione-benefici.html

¹²⁹ <https://www.regione.piemonte.it/web/temi/diritti-politiche-sociali/politiche-sociali/scelta-sociale-buono-per-domiciliarita>

Supporting a stable, skilled, motivated workforce

- ✓ In Sweden, the concept of Corporate Social Responsibility (CSR)¹³⁰ was highlighted by focus group participants as an important potential source of increased funding within the system. While Sweden's CSR efforts are predominantly focused on investing in countries with higher levels of poverty,¹³¹ CSR was also seen as a possible source of funding for national and local NGOs.
- ✓ In the United States, the approach of the platform Undivided¹³² (previously mentioned for its support to families of children with disabilities in balancing work and caregiving) is also seen as helpful in attracting and retaining support.
- ✓ In Flanders, Care Ambassadors play a role in promoting jobs in the care sector.¹³³ ¹³⁴ Between 2018 and 2021, an ESF-funded project by EVA bxl and national partners developed Culturally Sensitive Care Ambassadors to help close the gap between care supply and the needs of elderly people living in underprivileged areas of Brussels. The project maximised the potential of informal caregivers and unemployed immigrants by training them as care navigators.¹³⁵
- ✓ The European project WELL CARE¹³⁶ is being conducted in Germany, Italy, the Netherlands, Slovenia, and Sweden, to strengthen the support available to long-term care workers and informal carers. The project focuses on improving resilience and mental well-being and is expected to provide promising practice in this field.

¹³⁰ <https://www.swedenabroad.se/en/about-sweden-non-swedish-citizens/thailand/business-and-trade-with-sweden/sustainable-business--corporate-social-responsibility/>

¹³¹ <https://www.sida.se/en/for-partners/private-sector>

¹³² <https://www.undivided.io/for-employers/>

¹³³ Healthcare ambassador Candice De Windt: 'Organisations without staff shortages are often less hierarchical' – Background – Social.Net

¹³⁴ <https://care-er.be/nl>

¹³⁵ <https://evabxl.be/en/project/cultuursensitieve-zorgambassadeur-csza/>

¹³⁶ <https://wellcare-project.eu/about/>

- ✓ In several US states, initiatives are underway to support the recruitment and retention of Direct Support Professionals (DSPs), particularly for people with developmental disabilities. For example, in California, the Department of Developmental Disabilities has created an internship program for DSPs and is developing a DSP University, where DSPs can earn higher pay upon completion of each Tier of training.
- ✓ In North Carolina, the Department of Health and Human Services, in collaboration with the Community College System, is piloting an Advanced Training Certificate for current DSPs and those interested in pursuing a

career in the field. The program will initially be offered free of charge at three community colleges, with potential expansion to more colleges depending on its pilot.

- ✓ Other schemes to support and recognise DSPs include the National Alliance for Direct Support Professionals,¹³⁷ which provides training programs aligned with core competencies, as well as resources for DSPs. Another example, also from California, is the DSP Collaborative,¹³⁸ coordinated by two Regional Centres working with service providers in their regions to provide job information, advice, and resources for DSPs and service providers.




¹³⁷ <https://nadsp.org/>

¹³⁸ <https://dspcollaborative.org/>



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