

A Roadmap on Independent Living

European Network on Independent Living
- ENIL



Executive Summary

All indicators are showing that in the last decade the exclusion of disabled people has increased. The number of people confined to institutions has risen, the disability employment gap has climbed to new heights and the number of people in sheltered workshops has multiplied. The 'at risk of poverty rate' among disabled people and the disability education gap remain at dangerously high levels.

These trends, which will be evidenced by figures further below, represent a drastic failure in policy choices. Instead of investing in Independent Living Services like personal assistance, personal budgets and supported employment, institutions and sheltered workshops are receiving record levels of spending.

Our choices have drastic consequences to the individuals affected and to society at large. Institutions lead to exposure to violence and a reduced life expectancy. The unsustainable nature of services that segregate threaten public finances and are eroding trust in the welfare state. Millions of talented people are excluded from the labour market which threatens the competitiveness of our economies. In times where international organisations are under threat, we are breaking our commitments under the United Nations Convention on the Rights of Persons with Disabilities.

We are calling on decision-makers to break the path dependency we are trapped in and choose a better way.

The 18 Pillars of Independent Living are a beacon, lighting the road we have to take.

Disabled people require access to housing in the community, to work in the regular labour market, to legal capacity, to an accessible environment, to income and peer support and to education and training.

An important prerequisite is having access to personal budgets and personal assistance. Personal budgets give disabled people the freedom to purchase the services they need. Personal assistance is the one-on-one support that respects the disabled person's leadership.

We are asking for the adoption of a **European Independent Living Services Guarantee**, entailing a Council Recommendation on Personal Budgets and a Council Recommendation on Personal Assistance.

A European Independent Living Services Guarantee is very much needed, so that the European Commission can initiate a process with national governments on how to install effective and truly inclusive services.

It is the first step on a long road towards the full implementation of the 18 Pillars of Independent Living.

In Part I we will fully outline our case for a European Independent Living Services Guarantee. In Part II we will present a detailed rulebook on personal budgets and in Part III a detailed rulebook on personal assistance.

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Part I For a European Independent Living Services Guarantee

1. The state of disability inclusion

According to the available research, confinements to institutions have seen a step increase in the EU.

The 2024 Eurofound report “Paths towards independent living and social inclusion in Europe” found that the number of disabled people confined to institutions has increased from 709,682 a decade ago to 916,385, an increase of 29% (Eurofound 2024).

According to independent researchers, the number of confinements stood at 1,2 million in 2007 and at 1,4 million in 2020, which would be a 14% increase (Comp. Mansel & all 2007; Siska & Beadle-Brown 2020).

Many member states are replacing large institutions through smaller settings, called group homes. The three studies quoted do not count group homes as institutions. The true rate of institutionalisation is very likely much higher.

The European Disability Strategy 2010-2020, published in 2010, indicated that the employment rate of disabled people stood at around 50%. According to a study by the European Disability Forum, the employment rate in 2023 stood at 51,3%. In 2010, the employment rate of non-disabled people stood at 68,6%. Currently, it stands at 75,8%. Thus, while the employment rate of non-disabled people increased 7,2%, the employment rate of disabled people only gained 1,3%. In 2010 the disability employment gap stood at 18,6% and in 2023 at 24,5% (ENIL 2025d).

There is a pronounced disability education gap. According to EU statistics, in 2022, 22,2% of 18-24 year olds “with activity limitations” were early leavers from education and training compared to 8,4% of their peers “without activity limitation” (European Parliament 2022). In 2024, 44,2% of people in the same age range “with a severe disability” were early leavers from education and training (Eurostat 2025).

Partly because of the limited access to income from employment, disabled people are on average poorer than non-disabled people. Disabled people experience significantly higher poverty rates, in 2024 28,8% were at risk of poverty, compared to 17.9% of non disabled people (Eurostat 2025b).

Disabled people are significantly more likely to be homeless. In some EU member states a quarter of the homeless population report to have physical impairments and up to 60% to have a psychosocial impairment (OECD 2021).

These figures show that disabled people are strongly excluded. In some areas the exclusion is increasing.

2. Current systems of service provision and the cost of discrimination

A principal cause for the high levels of disability exclusion we are seeing are systems of service provision which reinforce exclusion. This has consequences for the individuals affected and for society. There is a cost.

2.1 Institutions

Institutionalisation makes the exercise of choice and control impossible because all aspects of life become regulated and it also excludes from all areas of life. Having a family, pursuing hobbies, work or education become impossible. Institutionalisation exposes people to violence. The Concluding Observations of the UN Committee on the Rights of Persons with Disabilities (CRPD-Committee) to Belgium found that confinement to institutions reduces life expectancy (Committee on the Rights of Persons with Disabilities 2024) . Nobody should have to lead such a life. Families should not be exposed to losing their loved ones.

Once institutionalised, it is very difficult to leave. Most people stay in the institution until the end of their life. For people who do leave, it is very difficult to find their way back into a normal life.

The costs of institutions to be borne by the public purse are high. Many EU countries are spending a high percentage of their GDP on long-term care. The Netherlands are spending 4,4%, Sweden 3,4%, Denmark 3,2%. Across the OECD average, nursing homes are responsible for half the cost but in many EU countries the share is much higher. For the Netherlands it is more than 80%, for France and Belgium it is over 60% (OECD 2023a).

The real costs are higher, because people confined to institutions have no way of contributing to society.

2.2 Sheltered employment

When it comes to employment, enormous resources are going into sheltered employment.

According to the study “Fostering employment through sheltered workshops: reality, trends and next steps” published by EASPD, the number of disabled people in sheltered employment has increased in many member states, for example in Finland from 15.805 in 2011 to 17.871 in 2021, in Spain from 56.332 in 2009 to 98.551 in 2021. In the Czech Republic the number increased by 14.500 in 2016 to 63.000 in 2021. In Germany the number of sheltered workshops increased from 688 to 734 in 2019. Approximately 320 000 disabled people work in the country's sheltered workshops (EASPD 2022).

ENILs' own research shows that significant financial resources are being used. The government of the Belgium region Vlaanderen has announced to spend EUR 30 million on sheltered employment to create 1000 additional places. Sweden is subsidizing the provider Samhall with EUR 500 Mio. Per year. Germany will invest at least EUR 33,34 million to build new facilities or renovate existing ones over the next years (ENIL 2025).

The European Commission study on alternative employment models for persons with disabilities, researched the effectiveness of sheltered employment and found that transition rates from sheltered workshops into regular employment are barely measurable. It was found that in Austria only 0,7% of persons working in sheltered workshops make the transition. For Germany studies indicate a transition rate of less than 1%. A study from 2023 by the Ministry of Social Affairs established a transition rate of 0,35%. For the Netherlands the rate is less than 1%, for Spain it is 0,55%. For Sweden, the transition rates are comparatively good and reach 6% to 7%

2.3 Social transfers

Being prevented from earning an income and trapped in poverty leads to a high dependency on the welfare state: In 2024, 68,2% of disabled people were at risk of poverty before social transfers and 20,7% after (Eurostat 2025).

While it is positive that social transfers are effective in mitigating the risk of poverty it is not a permanent solution. Relying on welfare benefits for subsistence is not pleasant for the individuals affected. It traps a person in a state of vulnerability and the accompanying bureaucratic demands are taxing. It does not lead to choice and control. Also it leads to higher costs for the public purse of financing the welfare state.

2.4 A wrong perception

Disabled people are not an inherently vulnerable part of society that is in need of constant tutelage. Once the barriers to societal participation are removed or at least reduced, disabled people make contributions that rival the contributions of non-disabled people. The Independent Living Movement is littered with such people.

The system of institutionalisation and the inequality in educational and employment outcomes, means that millions of talented people are excluded from making a contribution to our economies and our competitiveness. Countless ideas on artificial intelligence, renewable energies or engineering are lost. In a time where Europe is experiencing shortages of skilled labour and the competitiveness needs to be improved, we can not afford this waste of human resources any longer.

Systems of institutions and sheltered employment are well-established and generously financed. There is abundant evidence that the current systems of service provision are counterproductive. Exclusion is being produced, not reduced. The costs to the individuals and society are immense.

3. Independent Living Services

At the same time, services that could create inclusion and enhance choice and control are highly fragmented and limited in their effectiveness. The Independent Living Movement has been developing models of service provision, since its foundation.

In 1972, the first Centre for Independent Living opened in Berkeley and went on to define five core services: information, peer support, housing, equipment, personal assistance, transport and access. In 2010, the Hampshire Centre for Independent Living in the UK expanded the core services into the 12 Pillars on Independent Living which were expanded into 18 Pillars by ENIL in 2024:

1. Appropriate and accessible **information**
2. An adequate **income**
3. Appropriate and accessible **health and social care provision**
4. A fully accessible **transport system**
5. Full access to the **environment**
6. Adequate provision of **technical aids and equipment**
7. Availability of accessible and adapted **housing**
8. Adequate provision of **personal assistance**
9. Availability of inclusive **education and training**
10. Equal opportunities for **employment**
11. Availability of **independent advocacy and self-advocacy**

12. Availability of **peer support**
13. Availability of **supported decision making**
14. Awareness about the **Independent Living history and philosophy**
15. Full access to **sexual and reproductive rights**
16. Availability of **legal aid**
17. Full access to **digital technology**
18. Adequate support for life's **transitions** (childhood to adolescence, adolescence to adulthood, adulthood to old age)

3.1 Personal assistance

While all services are equally important, personal assistance can contribute to accessing many other services and rights. Personal assistance can be defined as a one-on-one support, based on the needs, wishes and authority of the disabled person. When personal assistance is provided, one or several personal assistants accompany the disabled person for as many hours during the day as needed and perform almost any task the disabled person asks for. This can involve help with getting dressed, cooking, cleaning, staying organised or remaining emotionally balanced.

Having personal assistance can enable a person to go to work, to education, to use transportation, to manage the house or manage life transitions.

Personal assistance is needs-based. Assistants stay for as much time during the day as required. Homecare services work very limited hours, which can make participation in working life impossible.

3.2 Personal budgets

The most important tool to access personal assistance are personal budgets. When holding a personal budget (PB) a disabled person receives a monthly amount of funding to purchase services needed for support.

Personal budgets (PBs) function according to the principle of demand driven support and are all about the disabled person taking control of the organisation of their own care and support. Personal budgets work according to the 'the budget follows the person principle'. Personal budgets have the objective of enabling the recipients to participate in society without having others make choices for them (European Commission 2024).

Personal budgets allow a disabled person to hire the assistants they prefer and ensure a power balance in her or his favour. Having full choice and control over who provides the assistance is essential to preserve the dignity of the disabled person.

Not every disabled person with support needs requires personal assistance. Personal budgets give freedom to purchase other services along the 18 Pillars of Independent Living.

3.3 The economic performance of Independent Living Services

It is often assumed that Independent Living Services, as described in the 18 Pillars of Independent Living, are more expensive than institutional care. There is evidence that this is not the case.

A study from 2010 found that: PBs can be economically advantageous compared to traditional supply-driven policies. Due to lower overhead costs, cost savings can be achieved (Da Roit & Le Bihan 2010). Institutions require the maintenance of large facilities and spending on an administrative bureaucracy. Independent Living services reduce the need for both.

A study from 2021 found that PBs challenge the traditional supply model, opening the way for new players which improve competition with positive effects on costs (Van de Eeckhout 2021).

A study from 2024 compared the direct cost of personal assistance to the cost of institutional care and found that personal assistance often costs the same and in some cases less. Factoring in societal benefits, recipients may become able to work or volunteer, makes personal assistance even more cost-effective.

Another study from 2024, using a sophisticated methodology, found that comprehensive support packages, consisting of community-based services, generate considerable savings (European Commission 2024).

Fully developed personal budget and personal assistance systems would significantly contribute to a higher employment rate of disabled people, improving access to income and reducing the dependence on social transfers. Next to savings due to lower expenses for social transfers, the availability of talented people to the economy would increase GDP.

3.4 User satisfaction

In addition, there is a high satisfaction of recipients. A survey from Germany (2007) found that 89% of users experienced positive changes since receiving the budget. Surveys from Belgium found that 90% to 86% stated that they very much need their budget. In a survey on the impact of personal budgets on quality of life, 63% stated

that PBs had given them more control of their care. In a survey from the Netherlands from 2021 74% of respondents indicated they would still opt for a PB if care in kind offered the same care because it grants greater freedom to plan the day. 29% experienced the allocation of the budget as negative, saying that the process had caused them a great deal of stress and took a very long time. 31% reported policy changes that limited the free use of their personal budget (European Commission 2024).

3.5 Services according to the UN CRPD

According to article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), disabled people are to have access “to a range of in-home, residential and other community support services, including personal assistance, necessary to support living and inclusion in the community”.

3.6 The state of Independent Living Services

3.6.1 Personal budgets

The ENIL Independent Living Survey 2024 researched the perceptions of disabled people on service provision by directly surveying disabled respondents. Study participants, disabled individuals and disabled people’s organisations, indicated that access to Independent Living Services remains on a low or very low level (ENIL 2024).

According to our information not many countries have nationwide personal budget systems. Nationwide personal budget schemes have been introduced in Sweden in 1993, in the Netherlands in 1995, in Germany in 2001 and in Belgium (Vlaanderen) in 2017. In Italy, Finland and Ireland small-scale pilot projects are being conducted. In many countries, including Germany, Belgium and Spain, implementation is very uneven between regions.

In Slovenia, the Personal Assistance Act provides the legal basis for personal funding as a pathway to independent living. Despite this framework, uptake has remained limited, with only a small pilot in the Maribor region and no widespread utilisation of personal budgets to date. As Slovenia moves toward strengthening community-based support, personal funding is expected to become increasingly important (ENIL 2019).

In Flanders (Belgium), a comprehensive Personal Budget Scheme (PVB) has been in place since 2017, allowing adults with disabilities to organise and manage their own support through the Flemish Agency for Persons with Disabilities (VAPH). The system builds on the earlier Personal Assistance Budget (PAB) for minors and is complemented by several person-centred initiatives: Global Individual Support (GIO) helps

young children with disabilities transition into education. The number of PVB holders increased from 25.399 to 30.315 between 2020 and 2025. The number of PAB holders increased from 1.129 to 2.450 in 2025. Efforts are underway to reduce the number of recipients (ENIL 2025c).

Southern Belgium does not have a personal budget scheme. The Brussels region has a personal assistance budget but is in the process of abolishing it (ENIL 2025d).

In Germany, the Personal Budget has been part of disability policy since 2001 and became a legal right in 2008 under the Social Code Book IX (SGB IX). It allows people with disabilities to receive direct payments instead of in-kind services, giving them control over how their support is organised and delivered. While the personal budget is used strongly in some regions, in others it is hardly used at all. (European Commission 2024)

The Netherlands introduced its personal budget system, the *Persoonsgebonden Budget* (PGB), in 1995 to give people with disabilities, chronic illnesses, or long-term care needs direct control over their support. Instead of only receiving state-arranged services, individuals can use their budget to choose who provides their care, when, and how (European Commission 2024).

In Denmark it is possible to have full-scale personal budgets. If it is personal assistance at the labour market, people with all kinds of impairments are entitled to receive a personal budget for personal assistance at the workplace. If it is personal assistance for living a life on equal terms with others it is dominantly available for people with mobility impairments. Over time, eligibility requirements have become stricter, reducing the number of potential recipients (EASPD 2019).

In Italy, personal budgets are implemented through regional and pilot initiatives rather than a single national system. In some areas, people with disabilities can use these budgets to fund personal assistance or community-based services, but access and funding remain uneven. The most notable example is Trieste's Community Mental Health model, internationally recognised for replacing institutional care with community-based support. Within this framework, Health Budgets are used by around 160 people to design personalised care while staying active members of their community. The approach has led to fewer hospitalisations, reduced involuntary treatments, and higher employment among service users. Across Italy, "individual health budgets" (*budget di salute*) initiatives are emerging, pointing toward greater autonomy and inclusion, though regional inequality, complex administration, and limited resources continue to hinder a fully rights-based personal budget system (OECD 2023b).

In Sweden, the Personal Assistance Budget (PAB) has been part of national law since 1993, through the Assistance Benefit Act and the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). Although there have been

growing concerns about tighter eligibility and regional inconsistencies, Sweden continues to stand out as one of the most established and rights-based personal budget systems in Europe (EASPD 2021a).

In Ireland, personal budgets are still in the pilot and development phase, following the government's Task Force on Personalised Budgets launched in 2016 (European Commission 2024).

Finland's personal budget system is still in the pilot and development phase, designed to increase choice and autonomy for people using disability services. The first experiments took place between 2010 and 2013, followed by a larger pilot from 2016 to 2019 across several municipalities, supported by universities and community organisations. After a pause during national reforms, the Ministry of Social Affairs and Health relaunched the initiative in 2020, to continue developing and testing the model (European Commission 2024).

In conclusion, implementation of personal budget schemes is very fragmented across the EU. We are far away from having well-established systems in every country. Personal budgets are not an established branch of social security or social protection. Thus, access to other services like personal assistance or peer support is restricted. In their current state, Independent Living Services are not strong enough to create meaningful effects for inclusion.

3.6.2 Personal Assistance

According to the ENIL Independent Living Survey 2022, within the EU, all countries have PA-schemes, except Luxembourg and Hungary. Greece is about to run a pilot PA project for a limited number of disabled people (ENIL 2022).

In many countries, the quality of PA provision varies considerably between administrative areas.

Twenty-five countries currently do not allow disabled people living in institutions to apply for personal assistance.

Many countries prioritize disabled people with certain types of impairment and discriminate against others. Disabled people with all types of impairments, who need personal assistance, must have access to it.

Twenty-six countries in Europe restrict the usage of PA. Restrictions defeat the purpose of PA to give disabled people full self-determination.

Thirteen countries do not provide funding in the way of direct payments or personal budgets. Direct payments/personal budgets are key in giving the disabled person full autonomy and make it clear for the PA who their employer is.

Fifteen countries do not provide PA based on the real needs.

In 22 countries, disabled people using PA can select and hire their assistants, while in 11 they cannot.

Many countries place eligibility and needs assessments exclusively in the hands of medical professionals who are likely to favour a medicalized view on disability rather than an approach based on the human rights model. In 29 out of 33 countries assessors do not receive training on Independent Living or the social model to those assessing needs of disabled people for PA. In 28 out of 33 countries, assessment procedures are not straightforward and transparent. Disabled people need to be able to trust the assessments. At the moment, trust is very low.

In the Czech Republic, personal assistance is currently only available for 4-5 hours per day. The limit in Slovenia is 30 hours, while in the Greek pilot project there is no limit, but the available payment cannot cover more than approximately 50 hours per week. Disabled people with support needs which exceed this limit might have no choice but to rely on family members or to move to an institution.

In 21 countries users are not allowed to keep their assistance when moving to another region or local authority within the country. Between EU countries, there is no portability of personal assistance at all. Assessments have to be repeated from the start. Non-disabled people who have, for example, reached pension age can take their pension entitlements with them when moving within and between countries. This inequality and discrimination puts disabled people at a significant disadvantage and is a significant barrier to their freedom of movement within the EU.

In 22 out of 33 countries, there is no quality control mechanism. It should be self-explanatory that the quality of service needs to be monitored. The planning and implementation of the provision should be co-produced with organisations of disabled people.

In 18 countries, peer support is not available, while in 16 it is. Access to peer support is crucial for the complete duration of the working relationship between assistant and the disabled person (Stainton & Boyce 2004).

4. Scope for EU action

The situation of exclusion of disabled people is in contradiction to core principles of the EU treaties. The treaties give the EU options to act.

4.1 The freedom of movement

According to article 45(1) of the Treaty on the Functioning of the European Union (TFEU), “Freedom of movement for workers shall be secured within the Union.” The free movement of workers is a fundamental principle of the EU treaties.

If disabled people can not work due to unmet support needs this means they are excluded from the freedom of movement. Without access to personal assistance and personal budgets it is not possible for disabled people to travel abroad to achieve the option of being able to be employed on the labour market.

4.2 Creation of employment

According to article 146 TFEU, member states “shall regard promoting employment as a matter of common concern and shall coordinate their action on this respect within the Council”. According to article 147(1) TFEU, “the Union shall contribute to a high level of employment by encouraging cooperation between Member States and by supporting and, if necessary, complementing their action”. According to article 147(2) TFEU, “The objective of a high level of employment shall be taken into consideration in the formulation and implementation of Union policies and activities.”

As shown before, the current system of disability services impedes access to employment.

4.3 Combating exclusion

According to article 3 of the Treaty on European Union (TEU), the Union “shall combat social exclusion and discrimination, and shall promote social justice and protection”.

According to article 9, “the Union shall take into account requirements linked to the promotion of a high level of employment, the guarantee of adequate social protection, the fight against social exclusion, and a high level of education, training and protection of human health”.

According to article 151, “the Union and the Member States ... shall have as their objectives the promotion of employment, improved living and working conditions, so as to make possible their harmonisation”.

According to articles 153(1), 153(1)(c), 153(1)(j) and 153(1)(k) “With a view to achieving the objectives of Article 151, the Union shall support and complement the activities of the Member States in the following fields:

- social security and social protection of workers
- The combating of social exclusion
- The modernisation of social protection systems

Article 153(2) grants the competence to adopt “by means of directives, minimum requirements for gradual implementation”.

4.4 Council recommendations

Article 292 TFEU, grants the EU Council the competence to adopt recommendations: “The Council shall adopt recommendations. It shall act on a proposal from the Commission in all cases where the Treaties provide that it shall adopt acts on a proposal from the Commission”.

4.5 Legal precedents

In June 2021, the European Commission proposed a Council Recommendation establishing a European Child Guarantee.

The European Commission based the proposal on the following legal provisions:

“The proposal is based on Article 292 of the Treaty on the Functioning of the European Union (TFEU), under which the Council adopts recommendations on a proposal from the Commission, in conjunction with Article 153(1)(j) and Article 153(2) TFEU.”

In September 2022, the European Commission proposed a European Care Strategy, which included the proposal for a Council Recommendation on access to affordable, high quality long-term care. The, albeit non-binding, legislation gave recommendations on how to design long-term care systems.

The European Commission based the proposal on the following legal provisions:

“The proposed Council recommendation is based on Article 292 TFEU in combination with Article 153(1)(k) TFEU, which allows the Union to act with regard to ‘the modernisation of social protection systems’”.

5. For a European Guarantee on Independent Living Services

To improve the inclusion of disabled people, to ensure the modernisation and sustainability of social protection systems and improve the competitiveness of our economies, it is essential to improve access to Independent Living Services.

We believe that the European Union should and can act to implement personal budget and personal assistance systems of high quality in the Member States.

The long-term goal has to be the adoption of directives, establishing minimum requirements for national systems, for the benefit of the social security and social protection disabled workers, in line with article 153(1)(c) and article 153(2).

To take a first step on the road to Independent Living, we call on the European Commission to adopt a European Guarantee on Independent Living Services. Such a guarantee should propose a Council Recommendation on Personal Budgets and a Council Recommendation on Personal Assistance.

Such recommendations would contribute to the combat of social exclusion and discrimination in line with article 3 TEU, to the promotion of employment, the guarantee of adequate social protection and the fight against social exclusion in line with article 9 TFEU.

The establishment of fully functioning personal budget and personal assistance schemes in the entire EU, would fundamentally alter the functioning of disability support systems and thereby modernise social protection systems in line with article 53(1)(k) TFEU. Given the enormous potential to improve social inclusion, such action would greatly contribute to the combating of social exclusion in line with article 53(1)(j) TFEU.

Such Council Recommendations should outline to member states the principles according to which personal budget and personal assistance systems shall function.

In part II of this document, we will make detailed proposals as to the functioning of personal budget schemes. In part III, we will make detailed proposals as to the functioning of personal assistance schemes.

Part II A Rulebook for Personal Budget Schemes

Personal budgets (PBs) give disabled people freedom to purchase the services they need. How should personal budget systems be designed to ensure maximum effectiveness in providing inclusion of disabled people and to guarantee choice and control?

To acquire the necessary expertise, three meetings of the Task Force on Independent Living took place in 2025 featuring expert presentations and discussions among the participants. To complement the insights derived from those sessions, desk research was undertaken.

Based on this input a number principles were identified according to which personal budgets should function.

1. Focus on services required for support

Which services can disabled people purchase under existing personal budget schemes?

In Vlaanderen it is allowed to purchase a place in an institution, by using the personal budget (PB). ENIL asserts that using the personal budget (PB) to pay for a place in a segregating service like institutions, group homes, special schools or kindergartens must be categorically forbidden.

In Finland, PBs can be used for day activities, rehabilitation, transport, and community-based support, but not for personal assistance, which remains funded separately. (European Commission 2024).

In Germany, the PB is based on individual needs and can be used for personal assistance, mobility, rehabilitation, or housing-related supports that promote participation and independent living (EASPD 2020a).

In the Netherlands, the PB can cover a wide range of supports, including personal assistance, household help, day activities, youth care, and nursing services, reflecting a strong focus on independence and flexibility (European Commission 2024).

Which services should be purchasable?

To ensure Independent Living, access to the 18 Pillars of Independent Living is required:

1. Appropriate and accessible **information**
2. An adequate **income**
3. Appropriate and accessible **health and social care provision**
4. A fully accessible **transport system**
5. Full access to the **environment**
6. Adequate provision of **technical aids and equipment**
7. Availability of accessible and adapted **housing**
8. Adequate provision of **personal assistance**
9. Availability of inclusive **education and training**
10. Equal opportunities for **employment**
11. Availability of **independent advocacy and self-advocacy**
12. Availability of **peer support**
13. Availability of **supported decision making**
14. Awareness about the **Independent Living history and philosophy**
15. Full access to **sexual and reproductive rights**
16. Availability of **legal aid**

17. Full access to **digital technology**

18. Adequate support for life's **transitions** (childhood to adolescence, adolescence to adulthood, adulthood to old age)

It is sometimes mentioned that help within and around the house is also important.

Rules to be followed

1. A firm link with personal assistance

For the Independent Living Movement, Personal assistance is the essence of personal budgets. The purchase of personal assistance has to be the priority. Hiring personal assistants from a budget allocated to a person, significantly contributes towards having full choice and control. According to General Comment No. 5 of the Committee on the Rights of Persons with Disabilities, the funding for personal assistance “is to be controlled and allocated to the person with disability with the purpose of paying for the assistance required” (Committee on the Rights of Persons with Disabilities 2017).

2. Access to other services required for disability support

For many disabled people it is important to have the freedom to use their personal budget to purchase other services than personal assistance. Having support within and around the house or in doing administrative work is important for many. Thus, it should be allowed to purchase other services along the 18 Pillars of Independent Living and beyond.

At the same time it is important to exclude services which are not directly linked to disability support like access to mainstream services or leisure activities.

2. Access for persons of all impairments and all ages

The Swedish system gives people with significant and permanent disabilities, including those with intellectual disabilities, the right to organise and manage their own personal assistance (EASPD 2021a).

In Vlaanderen there is a second type of personal budget specifically for children, with different rules and a separate application procedure (ENIL 2025c).

The Irish system primarily targets adults with disabilities who are eligible for or already receive Health Service Executive (HSE) funded support. This includes people with

physical, sensory, intellectual, or developmental disabilities, autism or significant support needs related to independent living. The focus is on individuals who require personal assistance. Children and older people are not currently included (NDA Ireland 2017).

In Finland the personal budget pilots mainly target adults with intellectual, physical, or sensory disabilities who already receive municipal disability services, with some projects involving older people and families of children with disabilities (European Commission 2024).

The German system is open to all persons with disabilities or chronic illnesses eligible under the Social Code (SGB IX), including children, adults, and older persons. In practice, however, most beneficiaries are adults, as support for children and older people is often provided through other care or social assistance schemes. (European Commission 2024).

In the Netherlands, PGB is open to children, adults, and older people with physical, sensory, intellectual, or psychosocial disabilities, as well as those with chronic or age-related conditions. Around 125,000 people currently use a PGB, most of them adults or older persons living independently. In The Netherlands, unlike in some countries, support does not automatically decrease after the age of 65, allowing people to continue managing their own care as they age (European Commission 2024).

Rules to be followed

Disabled people of all impairments and all ages need to be allowed to receive the budget.

3. A link to deinstitutionalisation

There is no evidence in any existing personal budget scheme of a link to deinstitutionalisation. A key purpose of personal budgets must be access to services that bring people out of institutions and prevent institutionalisation.

Rules to be followed

Personal budgets must never be provided while a person is confined to an institution or as a way to pay for a place in an institution.

Personal budgets must be linked to a deinstitutionalisation strategy. Personal budgets must be part of support packages which also include access to housing and income support, to people confined to institutions.

It is imperative to adopt annual targets of how many residents of institutions will be allocated personal budgets and other required services to leave the institution.

4. Parsimonious legal designs and full control

In the Netherlands, the personal budget is regulated through four different laws. The law on long-term care, the law on societal support, the care insurance act, the youth Law (PB for minors) (European Commission 2024).

In Germany, personal budgets are regulated through one legal act, the Social Code Book IX, (SGB IX) (EASPD 2021a).

Regulating personal budgets through different laws can create unnecessary red tape and unclear divisions of competence, complicating access.

Rules to be followed

Personal budgets should be regulated through one piece of legislation. In addition, it is important to ensure full self-determination over the use of the personal budgets.

5. Uniform implementation and independent review

In Sweden, depending on the number of assistance hours needed, support is financed either by the local authorities for under 20 hours per week, or by the Swedish Social Insurance Agency for more than 20 hours (EASPD 2021a).

Ireland's personal budget pilots are funded and overseen by the government, but their implementation relies heavily on Áiseanna Tacaíochta (ÁT), a civil society organisation. The government introduced personalised budgets through the Task Force on Personalised Budgets (2016–2018), yet a full administrative system for individuals to directly manage public funds is still missing (ESPD 2021a).

In Finland, personal budgets are fully government-funded and administered by municipalities and wellbeing regions, which assess needs, set budget amounts, and pay providers directly (European Commission 2024).

In Germany, the personal budget system is decentralised, with responsibilities shared across federal, regional, and local levels. The Social Code (SGB IX) defines the framework and rights, but implementation is carried out by municipalities and insurance funds, coordinated by a designated lead agency (*Leistungsträger*) when several authorities are involved. This structure allows flexibility and local adaptation to individual and regional needs but also results in differences in access and administration, depending on resources and local capacity (European Commission 2024).

The Dutch system is publicly funded and administered through several layers of government. Municipalities handle budgets under the Social Support Act (Wmo) and Youth Act (Jeugdwet), regional care offices (Zorgkantoren) manage those under the Long-Term Care Act (Wlz), and health insurers oversee care funded through the Health Insurance Act (Zvw) (European Commission 2024).

If personal budgets are defined by national legislation and implemented in regional and local authorities, uneven access can be the result. If implementation and application are centralised, authorities can acquire disproportionate power.

Rules to be followed

Personal budget schemes can be implemented by regional and local authorities. To ensure even implementation, the scheme needs to be established by national legislation and there needs to be nation-wide coordination between authorities.

In addition, an independent authority, for example an equality body, needs to be tasked with reviewing implementation and treating complaints by applicants and recipients. Should complaints procedures produce evidence of erroneous decisions or misconduct, the independent authority needs to have the competence to enforce its decisions. Implementation reviews and complaints investigations should be done by disabled people and their representative organisations.

Non-profit organisations, especially those led by disabled people, can play a key role in providing access to personal budgets. Their involvement helps ensure that decisions are guided by lived experience, promote autonomy, and remain centred on the preferences of the person rather than institutional interests.

6. Full legal capacity

In the Netherlands, recipients can appoint authorised representatives to handle PB matters. A legal representative can be appointed, parents or guardians, for under 18 years olds appointed by a judge (European Commission 2024).

Rules to be followed

Recipients may request support in managing their personal budgets. Such support must always take the form of supported decision-making. Substituted decision-making must never be permitted. Legal guardians must not be allowed to administrate PBs on a person's behalf.

7. Adequate financial resources

In Vlaanderen there is a long-term waiting list. The number of budget holders has been increasing but nevertheless there are waiting lists of up to 20 years with 18 302 people on it (ENIL 2025c).

Finland's personal budget pilots are fully government-funded through the Ministry of Social Affairs and Health. Earlier trials received about €15 million, and the 2020 phase allocated €2.9 million across nine regional projects (European Commission 2024).

Rules to be followed

If schemes are to be effective, the resources required to meet the needs of each applicant that qualifies need to be allocated. It needs to be taken into account that these investments will lead to additional revenues and lower costs long-term.

8. Needs-based budgets as a right

In Sweden, budgets are supposed to be calculated based on the actual number of assistance hours required, ensuring that funding reflects individual needs rather than standard packages (EASPD 2021a). However, authorities frequently look for means to allocate lower packages of assistance hours than legally required.

In Vlaanderen there are 24 budget categories. Budgets range from EUR 8.050,93 to EUR 107.295,56. While these budgets seem high, there is no direct link to real costs. Having 24/7 personal assistance support can generate substantial costs. Recipients end up paying some costs from their personal income. If incomes are low, that might make it impossible to use the personal budget (ENIL 2025c).

In Finland, budgets are set locally, based on the estimated cost of equivalent public services rather than fixed sums (European Commission 2024).

In Denmark it is, if necessary, possible to receive more than 24/7-personal budgets. (EASPD 2019a)

In several countries, personal budgets draw on both social care and health funding, recognising that many disabled people require supports that cross traditional sector boundaries. Without integrated funding, individuals with medical, technological or psychosocial needs may be unable to live independently.

The Trieste model in Italy illustrates this approach: its mental-health–focused personal budgets combine health and social welfare resources to support people in maintaining a home and accessing employment (EASPD 2021a).

Rules to be followed

Budgets need to be linked to real costs and based on the actual number of assistance hours required. The calculation of the personal budgets must be decided based on an assessment of the needs for services and therefore be flexible without any bottom or top level.

Payments must not depend on previous insurance contributions or similar requirements. It should function as a guaranteed right, not something contingent upon fluctuations in the public budget. Access to the payment should not be assessed against an individual's personal income or assets.

9. Support by family members

In Vlaanderen, 8,62% of recipients pay relatives to support them (ENIL 2025c).

To have self-determination, it is important to be able to choose who is providing the services, and therefore it should be possible for relatives to do this job.

Rules to be followed

It should be allowed to pay family members to provide support services like personal assistance.

While paying family members should be allowed, there must be a **clear basis** for when this is appropriate. Employing a relative is not always the best option, so criteria should explain why and under what circumstances it meets the person's needs and preferences.

10. Ensure fair application procedures

In Vlaanderen, the procedure to receive a 'the person following budget' starts with a request to the disability agency, VAPH. The first step is the preparation of a support plan. The applicant determines which support is needed and how it can be organised. What can the applicant do herself or himself? What kind of support can family members or people from the informal network do? Which regular services in the neighbourhood can lend support? What kind of support can only be realised with the support of VAPH? The support plan can be filled in by the applicant or a support plan service.

The second step is a review of the support plan by a multidisciplinary team. The team provides advice on the budget category on the basis of an objectification of the support need and the priority. In the third step, VAPH receives all documents and forwards them to a regional priority commission. The commission studies how urgent the support need is and places the applicant in one of three priority groups which determines how fast the budget will be awarded. The applicant receives a letter in which the results are communicated. As soon as there is a budget available the person can start receiving the PVB.

Rules to be followed

A proportionate application procedure is acceptable if the objective is to accommodate the person in becoming able to live a life on equal terms with others without impairment and based on the choice for life by the individual. The procedure should be quick and straightforward, and applicants should be able to complete it online or with in-person support if they prefer.

The perspectives of different groups, younger people, women or migrants need to be taken into account.

Those who are assessing the need for personal budgets need to be qualified and to respect the needs of those applying for personal budgets.

11. Support in administrating the personal budget

In Flanders, Service Support Plan Organisations (DOP) are tasked to assist people in identifying their needs and developing personalised care plans, and small-scale community projects such as Parents' and Green Care Initiatives promote inclusive, locally rooted solutions. Meanwhile, Bijstandsorganisaties (Assistance Organisations) are tasked to support budget holders with management, training, and advocacy, helping people exercise real choice and control without getting lost in bureaucracy (ESPD 2021a).

One of the most distinctive features of the Swedish model is JAG, a cooperative that helps people with multiple and intellectual disabilities manage administrative tasks and employ their assistants, while ensuring decisions remain in their own hands (ESPD 2021a).

In Ireland, ÁT is tasked to enable disabled people- called "Leaders"- to manage their own supports and employ personal assistants through direct payments from the Health Service Executive (HSE). To legally employ assistants and manage funds, each participant must establish a Company Limited by Guarantee (CLG), a small non-profit acting as the legal employer and handling payroll, insurance, and reporting. ÁT has the job to guide users through this process and provides peer to peer support networks. While the model has improved autonomy and satisfaction, access remains limited, with about 2,500 people currently receiving personal assistance for an average of 12 hours per week (ESPD 2021a).

In Finland, NGOs play an important developmental role in early personal budget pilots, particularly the *Finnish Association of Intellectual and Developmental Disabilities* and the *Service Foundation for People with Intellectual Disabilities* (European Commission 2024).

Rules to be followed

Organisations assisting recipients in administrating their budget are a key component in every personal budget scheme. This role should be fulfilled by Centres for Independent Living and User Cooperatives. Such organisations should be led by disabled people.

12. Mode of payment

In Flanders, Budgets can be received as cash, vouchers, or both, offering flexibility to choose between certified and non-certified providers. 14,34% of recipients receive cash budgets, 21,64% cash and vouchers and 62,98% vouchers (ENIL 2025c).

In Ireland, personal budgets are delivered as direct payments from the Health Service Executive (HSE) to individuals via Áiseanna Tacaíochta (ÁT). Participants, known as “Leaders,” receive these funds to employ personal assistants and manage their own support (European Commission 2024).

In Finland, participants do not receive the money as a cash payment. Instead, they work with local authorities to decide how their support is delivered and which services best meet their needs (European Commission 2024).

In Germany, personal budgets are publicly funded and calculated according to each person’s assessed needs, but their amount cannot exceed the cost of comparable in-kind services provided by the state. This ensures cost neutrality for public authorities while giving individuals flexibility and control over their support. Payments are usually made monthly as cash transfers, and recipients decide how to use them within their approved plan (ESPD 2021a).

In The Netherlands, payments are made via the Social Insurance Bank (SVB), which pays care providers directly on behalf of the person and ensures accountability. Budgets are set following a needs assessment and generally cannot exceed the cost of equivalent in-kind services (European Commission 2024).

Rules to be followed

Personal budgets can be paid out as direct payments or be provided in the form of vouchers.

Part III A Rulebook for Personal Assistance Schemes

ENIL defines Personal Assistance as a tool which allows for independent living. With the support of research, ENIL produced [a personal assistance checklist](#) setting out rules personal assistance schemes should follow. Between 2020 and 2022, ENIL conducted our [Independent Living Survey](#), collecting responses from 140 disabled people in 43 countries, to assess in detail how personal assistance schemes are functioning.

1. Needs-based funding

Ensure that funding for personal assistance (PA) allows disabled people to cover all their needs in practice. If they have to pay a share of the costs of their personal assistance out of pocket, this will inevitably lead to financial constraints, inequality and poverty, and thus reduces self-determination.

2. Disbursement through personal budgets

Resources to pay for PA must be dispersed directly to the disabled person in the form of direct payments, such as personal budgets. State parties need to ensure a low administrative threshold and should finance Centers for Independent Living (CILs) or PA user cooperatives which support PA recipients in working with their personal budget. Redirecting disabled people towards residential care, explained by the lack of funding for PA, must be categorically forbidden.

3. Access for people of all impairments and all ages

Provide equal access to PA to disabled persons with all types of impairments, including physical, cognitive, sensory, psycho-social and neurodivergent. In addition, personal assistance must be available to persons under 18 and over 65. Supported decision making must be provided to those people that need it for managing their PA.

4. Access to people in institutions

Disabled people in institutions, psychiatric hospitals and other residential care settings need to receive pro-actively allocated support in applying for personal assistance, to allow them to leave the institution and to exercise their right to live independently in the community.

5. Access to support

Ensure that disabled people applying for personal assistance have access to adequate information and/or peer support. Furthermore, disabled people using PA need to have the option to receive training by their peers and their representative organisations, on how to manage their assistance. While disabled people using PA need to have the right to train their assistants by themselves, some might want support with this task.

6. Choosing ones assistants

Ensure that disabled people can choose who provides the PA services, including that they are able to select and hire their assistants. The ability to choose one's personal assistant is rated as the number one feature of good personal assistance, since it enables choice and control (Comp. Mladenov 2019; Ratzka 2004).

7. Disabled led-assessments

Ensure that eligibility and needs assessments are led by disabled people and aided by peers and professionals. They should be straightforward and transparent. Committees in charge of assessment should be properly trained, including in independent living and the social model of disability. Without training, a medical perspective is likely to dominate assessments. Moreover, disabled people applying for personal assistance need to have access to fair and transparent appeal procedures and access to legal representation.

8. A right with uniform standards

To enable a life of self-determination, ensure that personal assistance is recognised as a right and provided according to uniformly high standards. Such standards should ensure, among other that:

There are no restrictions on what PA can be used for. For example, assistants must be permitted to perform tasks related to health care equipment, after appropriate training.

There are no cost ceilings per disabled person using PA. Cost ceilings lead to disabled people not having enough PA hours and to reliance on family members for support, or to disabled people having restricted lives.

The number of assistance hours per disabled person depends solely on individual needs. Disabled people should not be forced to live together with other disabled people, in order to share personal assistance, and due to inadequate hours.

Disabled people are able to determine the times when assistance will be provided without any restrictions. This is key in creating choice and control for the disabled person, including the freedom to, for example, accept a job where one has to leave the house at 5:00 in the morning or to go to meet people at the pub at 21:00 in the evening. In other words, any spontaneous activity, such as a walk in the forest, must be possible.

9. Personal Assistants as a career choice

Make being a personal assistant a more attractive career choice. Personal assistants need to receive wages competitive with other professions, social security entitlements and career development options. Moreover, there should be no specific qualification requirements and level of education to work as PA, but assistants should have access to training, which should be performed by disabled people themselves.

10. Raising awareness

Fund awareness raising campaigns to promote the job of a personal assistant. Such campaigns should aim to address myths around supporting disabled people, focusing on independent living, the contribution disabled people make to their communities and the society, and the role of a PA in this. Any campaigns should move away from a medical or a charity approach and embrace a rights based approach.

11. Ensure cross-border portability

Take concrete steps to ensure portability of personal assistance within the EU, as a precondition for disabled people to exercise their right to the freedom of movement. Ensure that disabled people are able to keep their assistance when moving within or between EU countries, and that their disability status is recognised for the purpose of accessing services and benefits for disabled people.

12. Monitoring by disabled people and their representative organisations

Put in place a quality monitoring system which allows the quality of PA provision to be monitored by disabled people and their representative organisations, including Centres for Independent Living, and by an independent body/agency.

PART IV A Rulebook for Centers for Independent Living

Centres for Independent Living (CILs) are user-led, cross-disability organisations that enable disabled people to exercise choice, control and self-determination when accessing Independent Living Services, in line with Article 19 UN CRPD. Their role is to ensure that rights and entitlements translate into practical autonomy, rather than dependency or segregation.

CILs are not traditional service providers. They function as enabling and accountability structures that support disabled people in using personal budgets, personal assistance and other Independent Living Services on their own terms.

ENIL has developed [a practical toolkit](#) on Centres for Independent Living.

1. User-Led Governance and Control

CILs must be led, governed, and strategically controlled by disabled people. Decision-making power must rest with users collectively, not professionals or service providers. “Nothing about us without us” is a binding operational principle.

2. Promotion of Choice and Control

CILs exist to strengthen individual and collective choice and control. Support must be organised around the person’s own priorities, life plans, and preferences. Disabled people define their own needs; professionals provide support, not direction.

3. Cross-Disability and Inclusive Approach

CILs must be open to disabled people with all types of impairments and of all ages. No hierarchy of impairments is acceptable. Services must be accessible to people with physical, sensory, intellectual, psychosocial, and neurodivergent impairments.

4. Opposition to Institutionalisation and Segregation

CILs must actively oppose institutionalisation in all its forms, including group homes and sheltered systems. They must not support or facilitate the use of personal budgets or public funds for segregated services. All activities must promote community-based, individualised support.

5. Peer Support as a Core Method

Peer support is a **foundational element**, not an add-on. Disabled people support each other through shared experience, strengthening confidence, skills, and autonomy. Peer support must be available throughout the entire Independent Living journey.

6. Support for Personal Budgets and Personal Assistance

CILs play a key role in enabling effective use of personal budgets and personal assistance. They provide assistance with administration while preserving full self-determination. Support must be based on supported decision-making, never substituted decision-making.

7. Intersectionality and Inclusion of the Most Marginalised

CILs must recognise and address multiple and intersecting forms of discrimination. Particular attention must be paid to disabled people facing compounded barriers due to gender, age, migration status, poverty, or institutionalisation. Outreach and accessibility are core responsibilities.

8. Accountability, Transparency, and Rights-Based Practice

CILs must operate transparently and ethically. They contribute to monitoring Independent Living Services and public spending. Their work is grounded in the human rights and social models of disability, not charity or medicalised approaches. CILs play a central role across all stages of Independent Living policy implementation:

- **Access and empowerment**
 - Providing accessible information on rights, services, and entitlements
 - Supporting disabled people to understand and claim personal budgets and personal assistance
 - Offering peer support and peer counselling grounded in lived experience
- **Implementation support**
 - Assisting disabled people in planning, organising, and managing personal budgets
 - Supporting the recruitment, training, and management of personal assistants
 - Acting as user-led intermediaries between individuals and public authorities
- **Deinstitutionalisation**
 - Supporting people in institutions to apply for personal assistance and personal budgets
 - Linking Independent Living Services with access to housing, income, and community life
 - Preventing the misuse of personal budgets to finance segregated services
- **Advocacy and monitoring**
 - Monitoring the quality, accessibility, and impact of Independent Living Services
 - Identifying gaps, discrimination, and systemic barriers
 - Holding public authorities accountable to national, EU, and UN CRPD obligations
 - Strong, adequately funded Centres for Independent Living are a necessary enabling condition for the effective implementation of Independent Living policies and services.

It is important to emphasize that intersectional work requires ongoing attention. CILs can benefit from regularly reflecting on their practices, gathering feedback from diverse users, and

identifying gaps that may still exclude certain groups. Investing in accessible communication, cultural competence, and collaboration with grassroots groups will continue to strengthen their impact.

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About the European Network on Independent Living

The European Network on Independent Living (ENIL) is a disabled-led, cross-disability network of disabled people and their representative organisations. ENIL promotes the right to independent living, as set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), its General Comments and the Guidelines on deinstitutionalisation, including in emergencies. ENIL's work is guided by the CRPD and the Independent Living principles, enshrined in the Independent Living Pillars.

ENIL is active at the European level, and internationally, through cooperation with Centres for Independent Living from around the globe. ENIL's actions and activities are based on the social and the human rights models of disability, and on the principles of inclusive equality, self-determination, solidarity and intersectionality.

ENIL has participatory status with the Council of Europe (i.e. is a member of the Conference of INGOs) and consultative status with ECOSOC.

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