

Independent Living in Europe: a right for all

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Personlig assistans och politisk påverkan

What is Independent Living?

*“Independent Living is having **same range of options and same degree of self-determination** that people without a disability take for granted.”*

Dr. Adolf Ratzka



[A Tribute to Adolf Ratzka](#)

UN Convention on the Rights of Persons with Disabilities (CRPD) and the role of General Comments

- Entered into force on 3 May 2008, the **CRPD** is a legally binding international treaty promoting and protecting the rights of persons with disabilities.
- The CRPD was **ratified** by all the EU Member States, the European Union and San Marino
- The **CRPD Committee** is the body of independent experts which monitors implementation of the Convention by the States parties
- **General Comments**, adopted by the CRPD Committee, provide authoritative guidance to the States Parties, and should be used by them to interpret their obligations under the CRPD



Why is the CRPD important?

- Legally binding: the CRPD sets out the **legal obligations** on States to promote and protect the rights of persons with disabilities. **It does not create new rights.**
- Paradigm shift: from medical to **social and human rights model of disability**
*'Disability is an **evolving** concept, and that disability results from the **interaction** between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others'*
- Through the **obligation to regularly report** on implementation, the CRPD provides States Parties and the civil society with an opportunity to review progress identify areas for improvement



[Human Rights Model of Disability](#)

Living independently and being included in the community (Art. 19, CRPD)



General Comment 5 – Key principles

- Refers to **ALL** disabled persons
- **Choice:** not limited to the place of residence, but includes all aspects of a person's living arrangements, incl. lifestyle
- **Rights-based approach:** IL as a right, instead of medical, social or charity care; right to choose services and service providers, with the aim to realise full inclusion within the community



General Comment 5 – Core elements



Independent Living in Europe

- Employment Equality Directive (2000/78/EC)
 - Defines “discrimination”, “indirect discrimination”, “reasonable accommodation”
- European Accessibility Act (2019)
 - Aims to improve internal market for accessible goods and services
- European Disability Card & European Parking Badge (2024)
- EU Strategy for the Rights of Persons with Disabilities 2021 – 2030
- European Pillar of Social Rights
- European Child Guarantee
- European Care Strategy
- Guidance on independent living (2024)
- Disability Employment Package

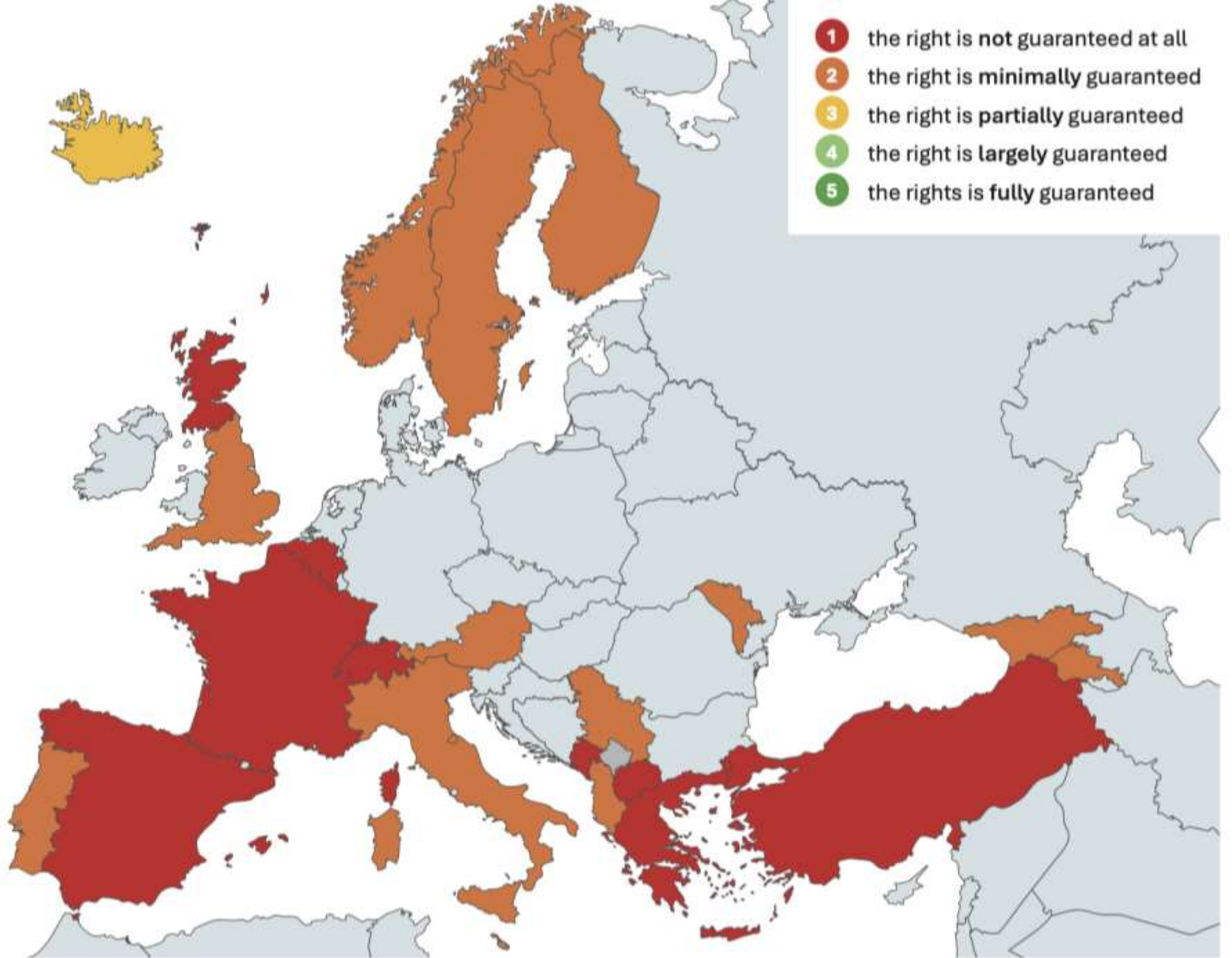


Independent Living Survey

- Detailed checklist for each Independent Living Pillar
- Score 1 – 5, based on lived experience

Albania	Iceland	San Marino
Armenia	Italy	Scotland
Austria	Luxembourg	Serbia
Belgium	Malta	Spain
England	Montenegro	Sweden
Finland	North Macedonia	Seitzerland
France	Norway	Turkey
Georgia	Portugal	
Greece	Rep of Moldova	





Scoring

COUNTRY	SCORE
Albania	2
Armenia	2.6
Austria	2.2
Belgium	1.8
England	2.1
Finland	2.4
France	1.3
Georgia	2.4
Greece	1.8
Iceland	3.2
Italy	2
Luxembourg	2.5
Malta	2.8

COUNTRY	SCORE
Montenegro	1.7
North Macedonia	1.7
Norway	2.3
Portugal	2.6
Republic of Moldova	2.6
San Marino	2.3
Scotland	1.9
Serbia	2.6
Spain	1.5
Sweden	2.9
Switzerland	1.9
Türkiye	1.7

Definition of Personal Assistance

- Person-directed/“user”-led human support
 - A tool for independent living.
 - Funding on the basis of personalized criteria and takes into account standards for decent employment
 - Based on an individual needs assessment and individual life circumstances
 - Must be controlled by the person with disability
 - One-to-one relationship
 - Can freely choose their degree of personal control over service delivery according to life circumstances and preferences
- Control can be exercised through supported decision-making



Common myths on PA

Any support at home can be called PA.

PA is not for children.

It is better to have family members as PAs, because they know you best.

Disabled people should pay for their PA.

PA is more expensive than institutions.

PAs could be dangerous for disabled people and harm them.

PAs need training and medical knowledge. They should have specific qualifications.

PA is only for people with physical impairments. Other disabled people cannot manage their PA.



Funding PA

- GC 5: “the funding is to be controlled by and allocated to the person with disability with the purpose of paying for any assistance required”



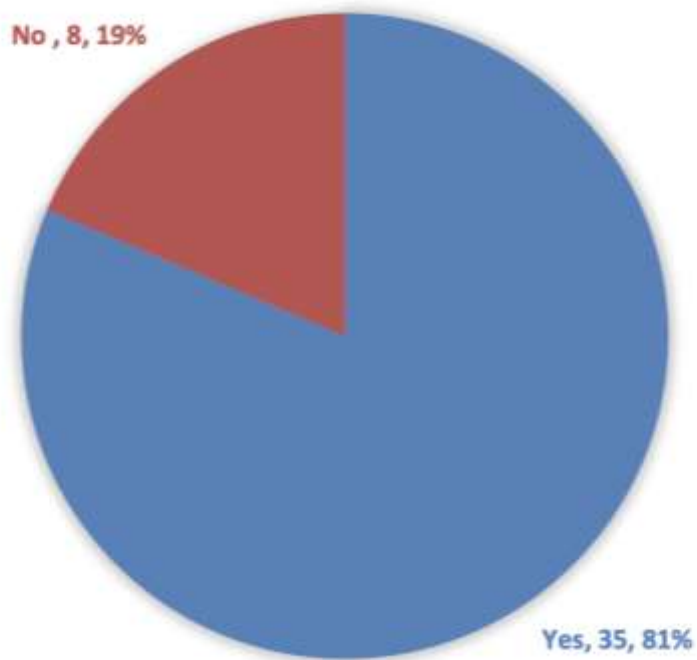
Personal budgets/direct payments

What should the personal budgets do?

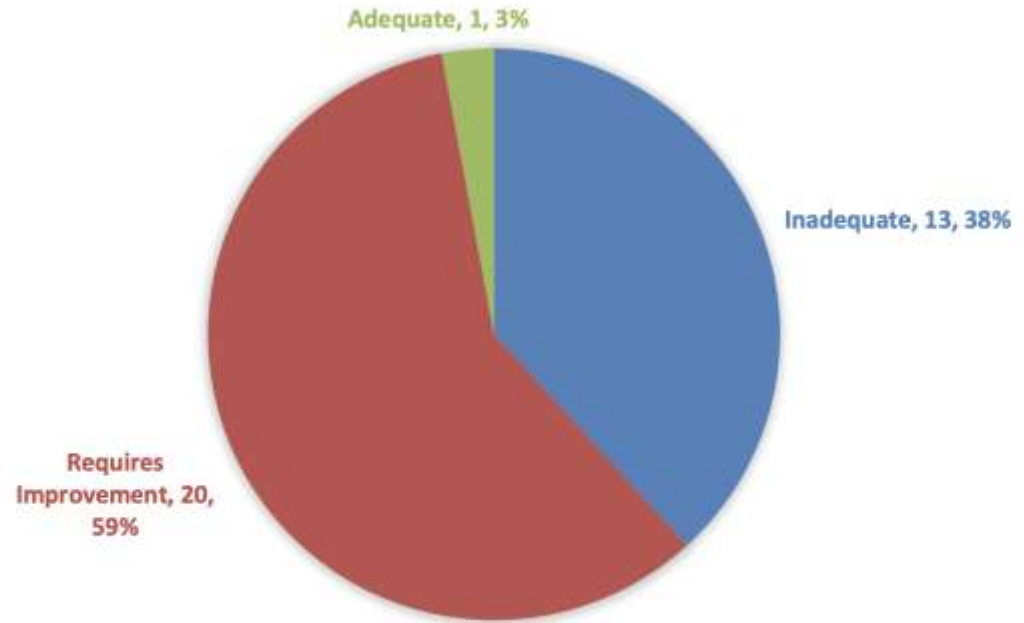
- The person can buy the support they need
- Cover the costs of employer's contributions and payroll work (administration)
- Cover other expenses related to PA (transport, food when going out, tickets for events etc.)
- Provide an incentive to buy PA and/or other community-based support services
- Discourage residential care options
- Come with peer support and/or supported decision making



Countries with publicly funded PA schemes



How good is the PA scheme



PA Checklist

What are the characteristics of a good, user-led Personal Assistance scheme?

There are differences in:

- Funding arrangements
- Needs assessment procedures
- Principles of provision
- Accountability requirements
- Working conditions of the assistants

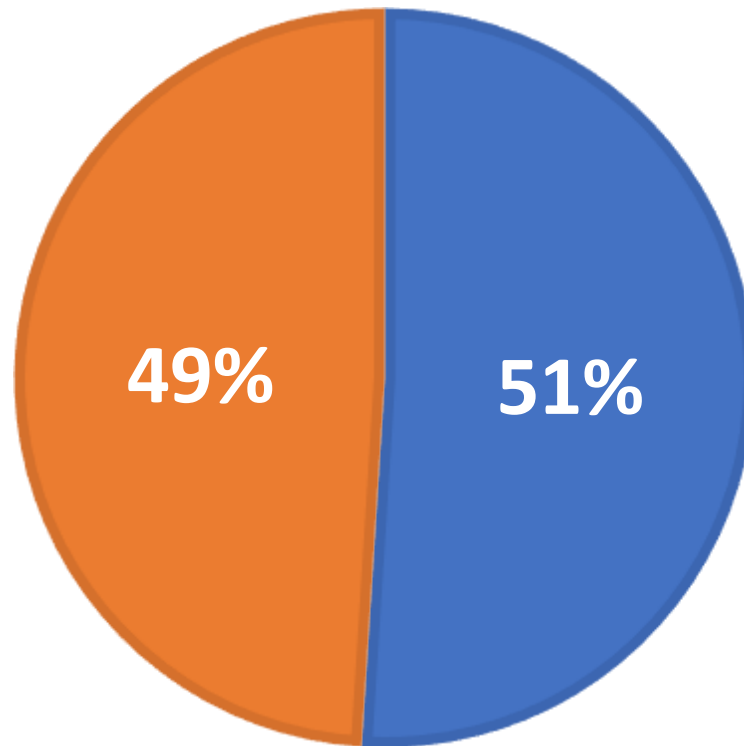
See: https://enil.eu/wp-content/uploads/2022/03/Mladenov_Pokern_Bu lic-PA_Checklist.pdf



PA CHECKLIST –
A Tool
for Assessing
Personal Assistance
Schemes

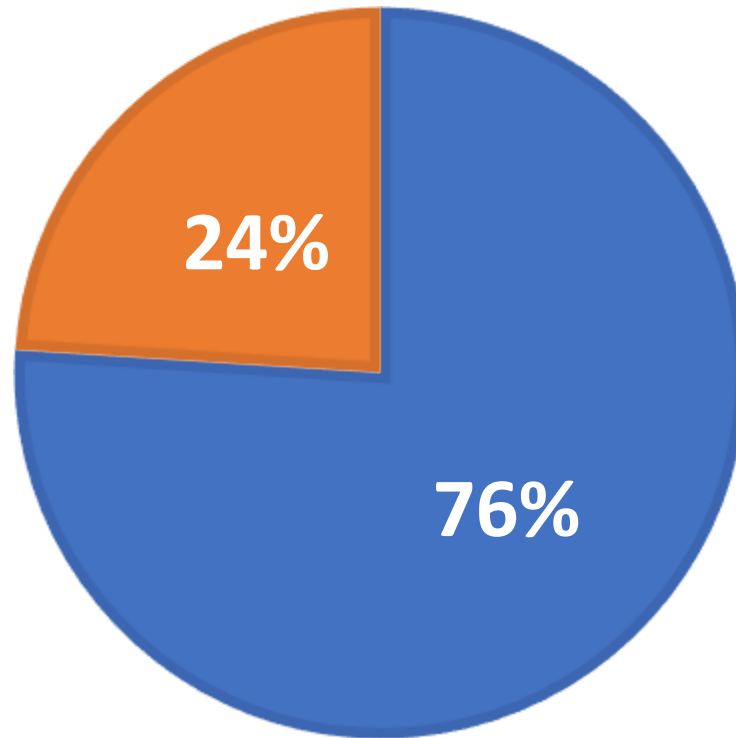
Employment of disabled people in the EU

■ Employed ■ Unemployed

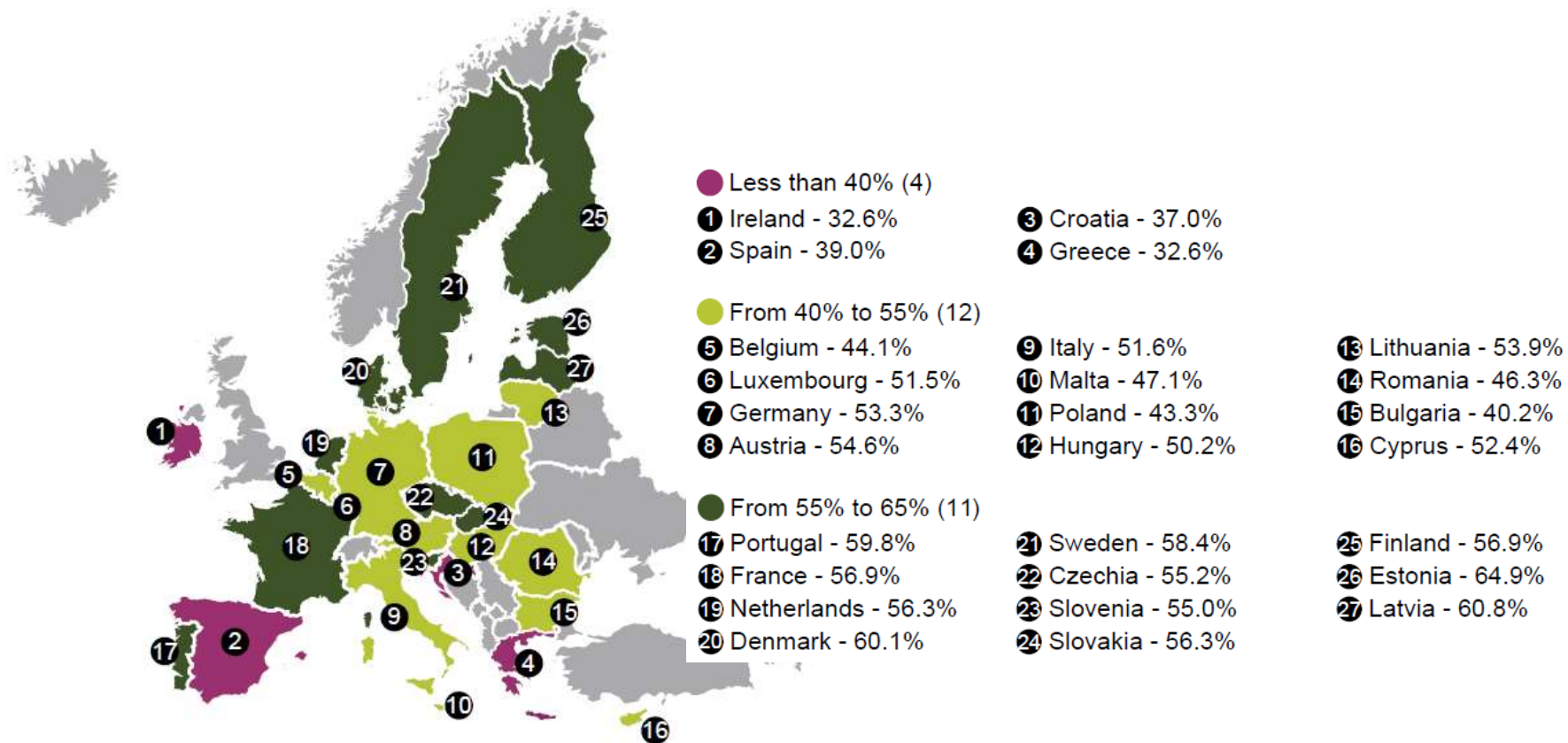


Employment of non-disabled people in the EU

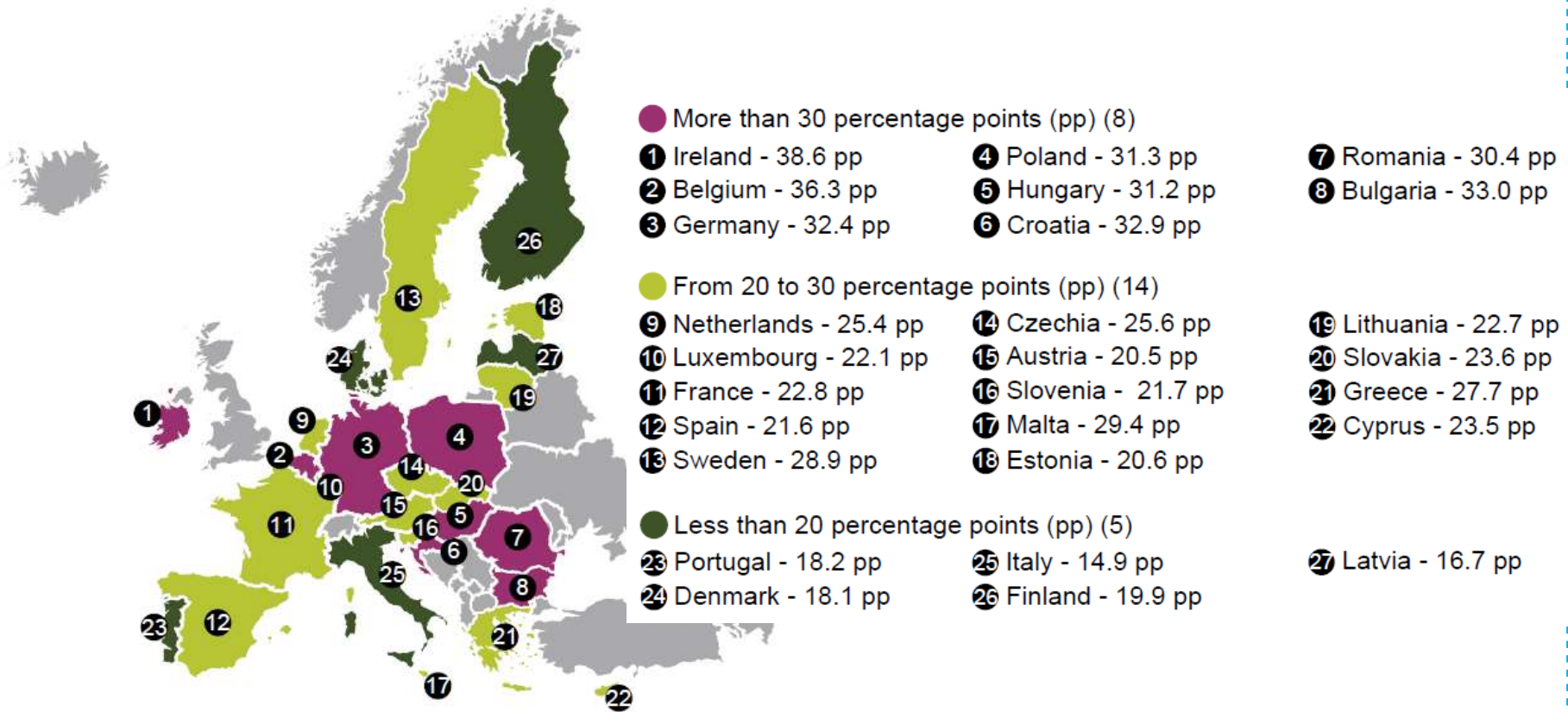
■ Employed ■ Unemployed



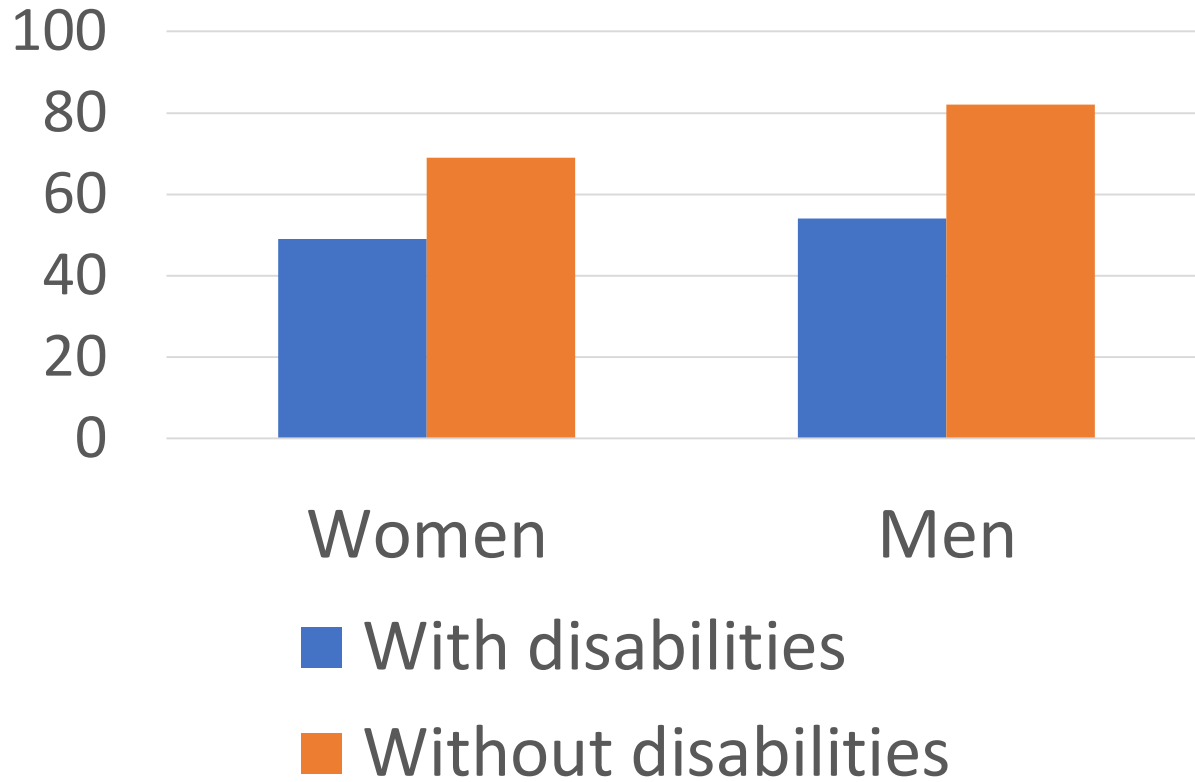
Employment rates of persons with disabilities in the EU Member States¹⁰



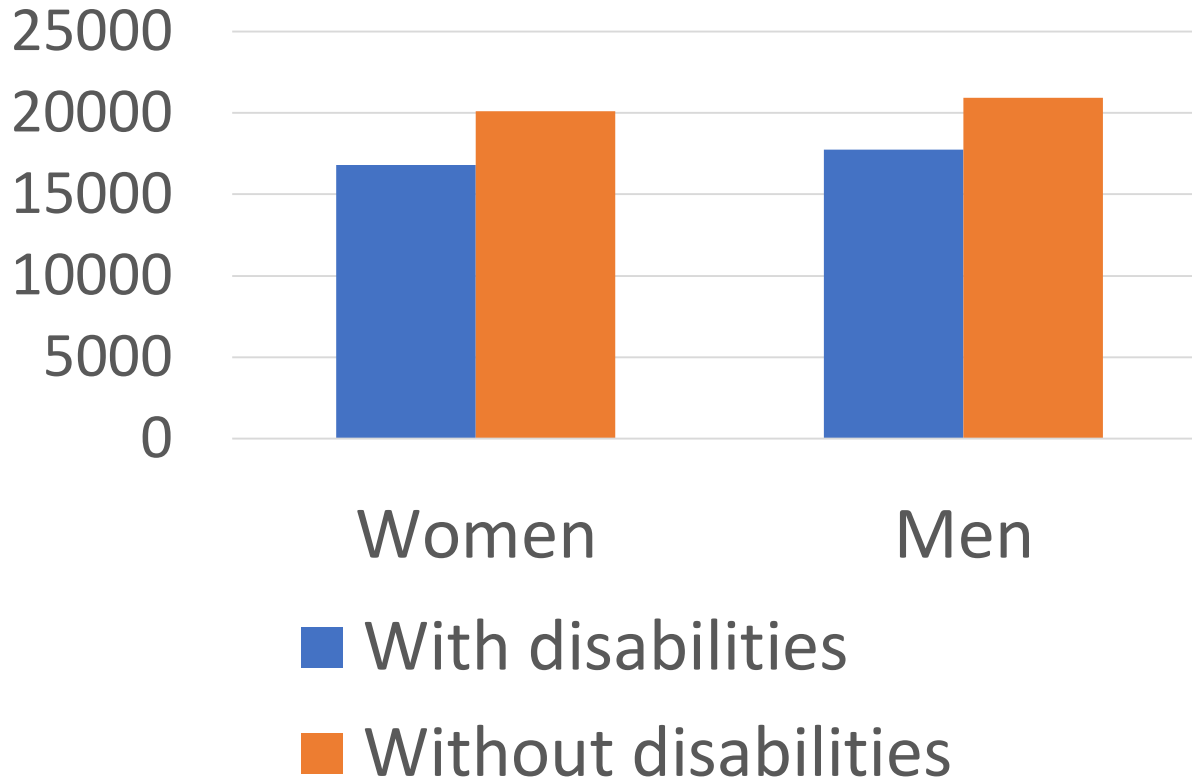
Disability employment gap in the EU Member States in percentage points (pp)¹⁴



Employment rates in the EU

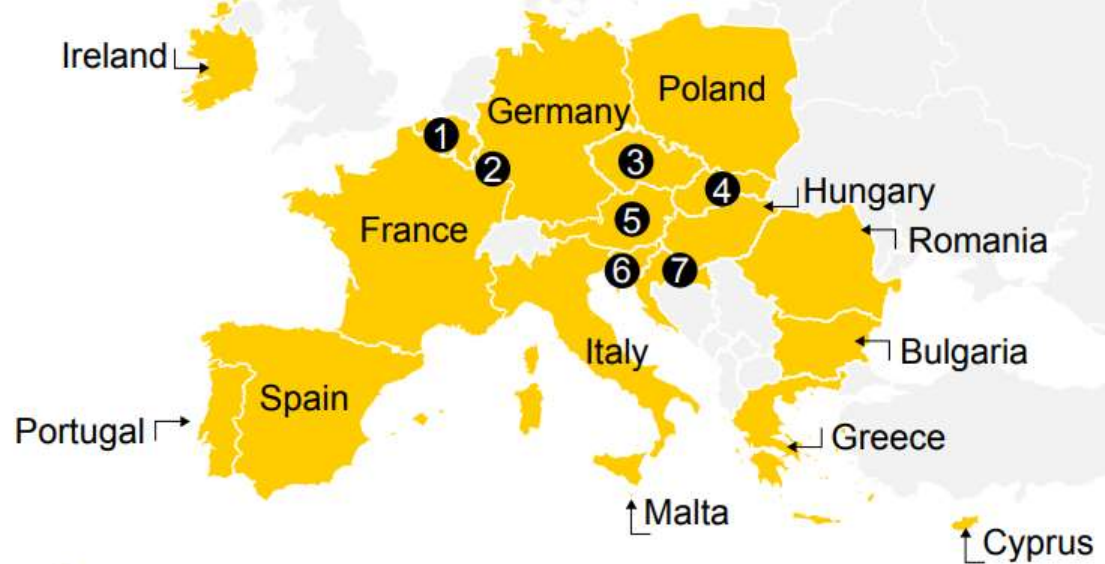


Income of women and men in the EU



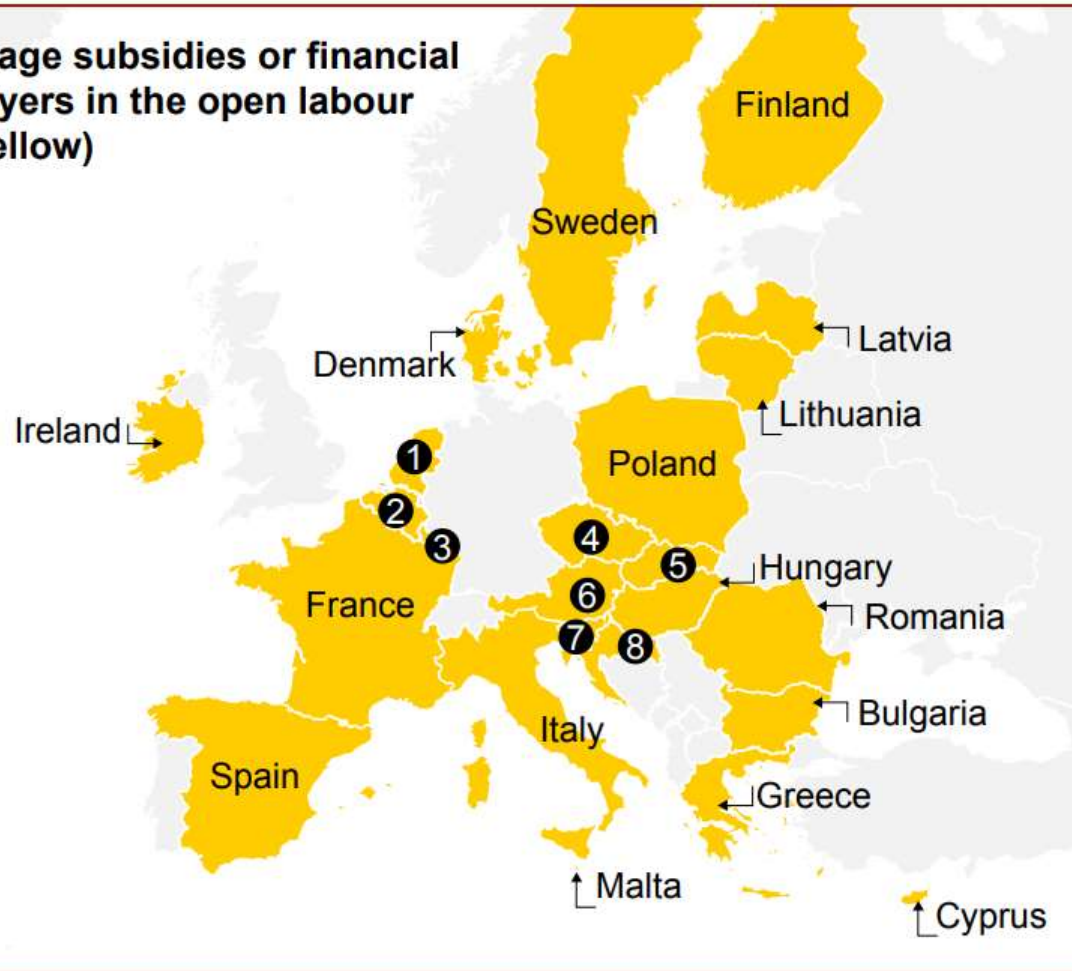
Countries with quota systems (marked in yellow)

- ① Belgium
- ② Luxembourg
- ③ Czechia
- ④ Slovakia
- ⑤ Austria
- ⑥ Slovenia
- ⑦ Croatia



Countries offering wage subsidies or financial incentives for employers in the open labour market (marked in yellow)

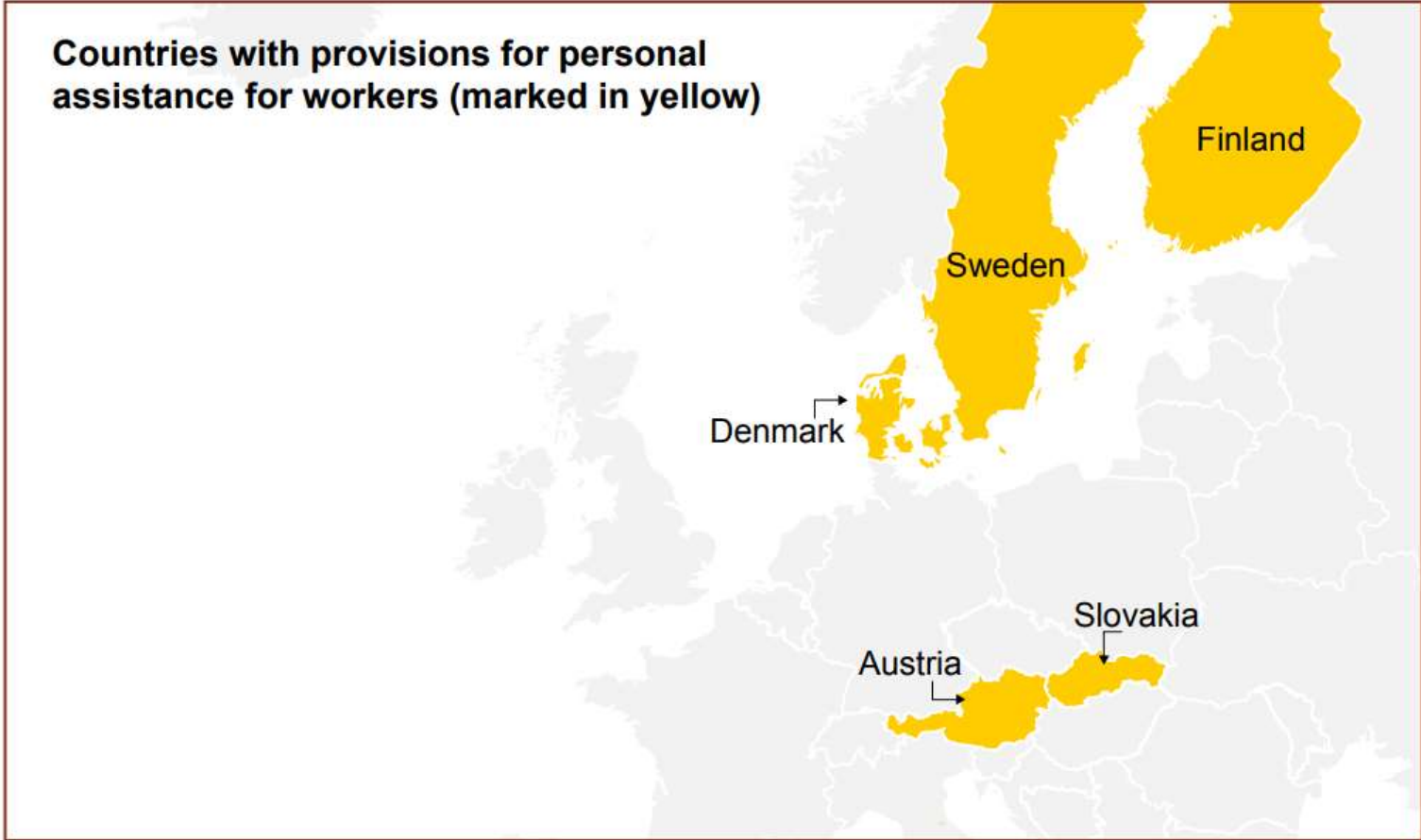
- ① The Netherlands
- ② Belgium
- ③ Luxembourg
- ④ Czechia
- ⑤ Slovakia
- ⑥ Austria
- ⑦ Slovenia
- ⑧ Croatia



**Countries offering tax reductions
(marked in yellow)**



Countries with provisions for personal assistance for workers (marked in yellow)



EU Member States that provide support for reasonable accommodation in the form of grants, tax subsidies or direct provision of equipment, etc.



- **work-related activities does not affect disability allowance:** Bulgaria, Cyprus, Czechia, Germany, Finland, France, Croatia, Hungary, Greece, Spain, Italy, Lithuania, Latvia, Malta, Romania and Slovakia.
- **Ceilings apply to the work-related income for some benefits:** Germany, Finland, France and Italy. In other countries, the interaction between disability-specific cash benefits and income from work results in reductions in the benefit. Such is a case in Austria, Belgium, Estonia, France, Lithuania and the Netherlands.
- **Not possible to combine disability allowance and salary:** Luxembourg, Portugal, Sweden, Slovenia, Albania, Montenegro, North Macedonia and the UK.

Policies that seem to work well and not so well

- Study being done by the European Disability Expertise network
- Shows correlation between countries with better employment rates of persons with disabilities and the policies they use

Effective measures

Following measures seem to be used in countries with better employment outcomes

1. Wage subsidies
2. Indirect wage subsidies
3. Allowing disability allowance alongside salary



Less effective measures

- Quotas used among some of the countries with highest disability employment gaps
- suggests that introducing legal obligations for employers rather than active labour market measures with public financial support might be less effective



Even less effective measures

Present in countries with poor employment outcomes for persons with disabilities were:

- Financing of sheltered workshops (show poor outcomes to support transition to the open labour market)
- Reductions in the benefit system through stricter evaluation to pressure more people into work



Thank you!

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