

European disability policy

From defining disability to adopting a strategy



IN-DEPTH ANALYSIS

This publication provides an overview of European Union (EU) disability policy. It addresses the issue of defining disability at national, European and international level, summarises the difficulties of measuring disability and presents some statistics, describes the EU's activities with regard to people suffering from a disability and sets out the European Parliament's positions on the matter.

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EXECUTIVE SUMMARY

The term 'handicap' originated from the English 'hand in cap' and was first used in horseracing vocabulary. It referred to a technique designed to restore the equality of all the horses by handicapping those with the best track record with extra weight. Over the centuries, the meaning of the word was inverted and it came to signify an economic, social or physical disadvantage.

After the International Classification of Impairments, Disabilities and Handicaps (ICIDH) was created in 1980, the World Health Organisation adopted a new definition based on the idea of 'functioning' in its 2001 'International Classification of Functioning, Disability and Health' (ICF). Similarly, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) kept a very broad definition of 'disability' in 2006.

There is no European Union (EU) definition of 'disability', and definitions vary from one Member State to another, and even within single Member States. Nevertheless, since the UNCRPD was signed by both the EU and its Member States, the definition provided by the UN has become the common reference.

Bearing in mind that there is no 'harmonised' definition of 'disability' in the EU, and taking into account the wide variety of statistical surveys in terms of both the questions asked and the population used, it is impossible to make a complete statistical assessment of disability in Europe. However, the European Survey on Health and Social Integration of 2012-2013 reveals the dividing lines on disability in Europe. The prevalence of disability is higher among female, older, or less educated respondents.

Alongside and in support of national policies, the EU made an undertaking to combat all forms of discrimination. In this context, and to improve the situation of disabled people, it has introduced a series of initiatives, programmes and strategies over a number of decades. It was from the 1970s that disability policy took on a European dimension. In 1997, the Treaty of Amsterdam, specifically Article 13 on the human right not to suffer from discrimination on the grounds, in particular, of disability, paved the way for a genuine disability policy. An action programme to combat discrimination was adopted in 2001-2006, and 2003 was dedicated 'European Year of People with Disabilities'. In 2010, the EU published a new 'European Disability Strategy 2010-2020' enabling disabled people to exercise their rights in full and participate fully in the society and economy in which they live. A number of initiatives were set up on the back of that strategy, including the European Disabilities Forum, an EU disability card scheme and a directive on accessibility of goods and services. The European Parliament has been highly active in the bid to end all forms of discrimination against disabled people since the start of the 1980s.

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1. Defining and measuring disability

1.1. Defining disability

1.1.1. Origin and understandings of the term 'handicap'

Originally, the term 'handicapped' did not refer to those who lacked something, but to those who performed better than others. It has been used in gambling since the 16th century and is therefore associated with the principle of a level playing field. At race tracks, stronger competitors are handicapped to reduce their chances of winning by adding extra weight before the start of the race. That levels the odds. With the outcome of the race having become uncertain, bets can be placed at random again. It amounts to putting the name of each horse into a hat and picking out the winner: 'hand in cap'!

It is not known exactly when, how and why the term went from referring to the limitation of the best horses' ability to human ability, but over the centuries the terms 'handicap' and 'handicapped' came to replace the more pejorative and degrading terms (see the box below)¹.

History and representation of disability

The way in which disability is talked about and understood is rooted in social, cultural and historical context². In ancient times, deformity was considered a sign of the wrath of the gods. In the Middles Ages, poor people, disabled people and thieves were grouped into the same category: the needy. Disability continued to be associated with guilt and divine punishment, although people with dwarfism, severe mental disabilities or kyphosis were given a particular status. As medicine progressed between the 16th and 19th centuries, people with disabilities were soon detained and isolated³. At the same time, some became living exhibits at fairs, a practice which lasted until the start of the 20th century. The 20th century saw efforts to bring about equality between people with disabilities and those without.

The change in perspective on disability can be seen through works of art. Literature has been as an essential vehicle for social representations of disability, with characters varying from one type of disability to another. Oedipus, who gouges out his eyes, is a typical example of the ancient relationship with disability. If novels and stories do feature disability, it is usually secondary characters who are affected. The following titles are examples of the many works of fiction which feature disability: The Hunchback of Notre-Dame (Victor Hugo, 1831), La Symphonie Pastorale (André Gide, 1919), Beware of Pity (Stefan Zweig, 1939), Flowers for Algernon (Daniel Keyes, 1960), The Curious Incident of the Dog in the Night-Time (Mark Haddon, 2003), The Solitude of Prime Numbers (Paolo Giordano, 2008), Nemesis (Philip Roth, 2012) and Sur les chemins noirs (Sylvain Tesson, 2016). The biographical genre marks a profound social evolution. It has developed since the 1950s, in particular with My Left Foot (Christy Brown, 1954), The man who walked in his head (Patrick Segal, 1980), Emergence: labelled autistic (Temple Grandin, 1986), Préfet des autres (Jean-Christophe Parisot, 2011) and Triso et alors! (Éléonore Laloux, 2014).

The first filmmakers played on people's fear of disability. The first film known for featuring a disabled person or people was *Freaks* (1932). Since the end of the 1980s, Hollywood productions have released more and more films and hired stars and famous actors to portray disability

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¹ Some examples are 'abnormal', 'backwards', 'crazy', 'crippled', 'deficient', 'deformed', 'dependent person', 'feeble', 'handicapped', 'halfwit', 'hunchback', 'idiot', 'infirm', 'invalid', 'lame', 'lunatic', 'maladjusted', 'malformed', 'mongoloid', 'mutilated', 'paralysed', 'paralytic', 'person of reduced mobility', 'retard', 'spastic', 'unable'.

² Cagnolo M.-C., <u>Le handicap dans la société: problématiques historiques et contemporaines</u>, *Humanisme et Entreprise*, No 295, 2009/5.

³ See in particular Michel Foucault, <u>Histoire de la folie à l'âge classique</u>, 1972.

without stigmatising it. Examples include *Elephant Man* (1980 with John Hurt), *Rain Man* (1988 with Dustin Hoffman), *Forrest Gump* (1994 with Tom Hanks) and, more recently, *The Intouchables* (2011 with François Cluzet and Omar Sy).

Pictorial representations of disability are many and varied⁴. For instance *Ship of Fools* by Jérôme Bosch, *The Blind Leading the Blind* by Pieter Brueghel the Elder, *The Healing of the Lame Man* by Raphaël, *The Blind Men of Jericho* by Poussin and *Quasimodo* by Antoine Wiertz.

From then on, the term 'handicap' [translator's note: in French] has been widely used to denote a disadvantage, be it economic, social or physical.

Since the 1960s, there have been two main ways of thinking about disability: the medical model and the social model. Each model is based on a different idea about the relationship between an individual's health and the environment in which they live:

- The medical model focuses on the person's medical condition illness or injury –
 which is the direct cause of their disability and may have an impact on their
 quality of life. A medical intervention may be necessary to diagnose and treat the
 disability and/or to maintain or increase the person's abilities.
- The social model focuses on the barriers created by society. Those may be
 physical or social restrictions, which prevent the abilities physical, social or
 professional –, which each individual needs to thrive.

1.1.2. International context

In 1980, the World Health Organisation (WHO) adopted the International Classification of Impairments, Disabilities and Handicaps⁵ (ICIDH) in which disability is understood as a person's ability, or lack thereof, to perform the social, economic and civil roles required of everybody in their daily lives. This means that environment creates disability, although it does of course originate from impairment. The ICIDH therefore goes beyond the conventional medical model making up the International Classification of Diseases (ICD⁶) by highlighting the impact of environmental and social norms on the disability process.

Based on Dr Philip Wood's model⁷, the ICIDH combines three aspects of disability to formulate the social and medical model:

- impairment: structural or functional anomaly in the body (e.g. amputation, spinal cord injury, auditory or optical nerve deficiency, paraplegia);
- disability: restriction of the person's activities owing to a deficiency (e.g. inability to hear, walk, see, stand up or talk);
- handicap: restriction of the person's ability to perform their social role in full (e.g. earn a living, study, work).

⁴ See in particular Blanc, A. and Stiker, H.-J., *Le handicap en images. Les représentations de la déficience dans les œuvres d'art*, Toulouse, érès, 2003; Korff-Sausse, S., *D'Œdipe à Frankenstein*, Paris, Desclée de Brouwer, 2001; Bonnefon, G., *Handicap et cinéma*, Lyon, Chronique sociale, 2004.

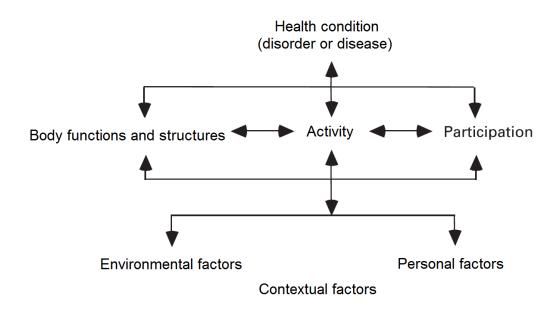
⁵ International Classification of impairments, disabilities, and handicaps: WHO, 1980.

⁶ International Classification of Diseases (ICD) -11th revision, WHO, 5 May 2012.

⁷ 'Professor Philip Wood: epidemiologist', <u>The Times</u>, 4 September 2008.

To take that further and unify the two disability models – the medical and the social – by creating a new three-dimensional model⁸, the WHO replaced the ICIDH with the International Classification of Functioning, Disability and Health (ICF)⁹ in 2001. It combines biomedical, psychological and social models and creates a common vocabulary and descriptive framework for the term 'functioning' (see Diagram 1).

Diagram 1 – Representation of the disability model of the International Classification of Functioning, Disability and Health (ICF)



Reference: WHO, 2001.

European disability policy

The purpose of the ICF is to establish an open classification taking into account three aspects of an individual's 'functioning':

- body functions;
- functions related to the person's activities;
- functions which enable the person to participate in society.

On the basis of those three basic dimensions – body, activity and participation – the ICF model integrates the medical dimension of health conditions while referring to the context in which the individual lives and the society to which he or she belongs.

In line with the ICF, the UNCRPD of 2006 adopted a very broad definition of disability (see box below):

'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (Article 1).

⁸ Jamet, F., <u>De la Classification internationale du handicap (CIH) à la Classification internationale du fonctionnement de la santé et du handicap (CIF), La nouvelle revue de l'AIS, No 22, 2003.</u>

⁹ <u>The International Classification of Functioning, Disability and Health</u>, World Health Organisation, 27 January 2017.

The United Nations Convention on the Rights of Persons with Disabilities

The Convention¹⁰ was adopted by the United Nations General Assembly on 13 December 2006. It came into effect on 3 May 2008, 30 days after it had been ratified by the 20th country. It did not create new rights, but reaffirmed the commitment to promoting, protecting and safeguarding the fundamental rights of disabled people.

By 2017, the Convention had been signed by 140 countries and the Optional Protocol by 90, and 95 countries have ratified it. It has 50 articles and lays down a number of guiding principles:

- Respect for dignity, individual autonomy and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference;
- Equality of opportunity;
- Accessibility¹¹;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

1.1.3. Broad national differences

In the EU, the definition of disability varies drastically from one country to another owing to their different historical, cultural, economic and social contexts.

When it comes to defining disability, therefore, some Member States adopt an entirely social approach, some a partly social approach, and others focus primarily or entirely on the medical aspect of disability¹².

While the countries differ in their approach to disability, they also differ in their 'codification'. Some Member States have established a legal framework which serves as a reference for all disability policies. In Germany, for example, the definition of disability which is used as reference appears in book 9 of the German Social Code (SGB IX), which came into effect on 1 July 2001. A person is 'disabled' when their bodily functions, mental abilities or mental health deviate, for more than six months, from the condition typical for a given age so that participation in society is impaired (Article 2(1), SGB IX)¹³. In Spain, disability is defined in Article 7 of Law 13/1982 on Social Integration of Disabled Persons (LISMI¹⁴).

Other Member States, such as Belgium, the Czech Republic, Denmark, Greece, Poland, Slovakia and the UK have no general legal framework for the definition of disability. 15

¹⁰ Convention on the Rights of Persons with Disabilities and Optional Protocol, United Nations, 13 December 2006.

¹¹ Qu'est-ce que l'accessibilité ? (What is accessibility?).

¹² <u>Definition of Disability in Europe: A Comparative Analysis</u>, A study prepared by Brunel University - Social security and social integration, European Commission, 2004.

¹³ G. Igl, <u>Les droits des personnes handicapées en Allemagne : les changements apportés par la nouvelle législation</u>, RFAS No 2, 2005.

¹⁴ <u>Les politiques en faveur des personnes handicapées en Espagne, aux Pays-Bas, au Royaume-Uni et en Suède</u>, Études et Résultats, DRESS, No 305, April 2004.

¹⁵ Falek H., <u>Tour d'Europe des définitions du handicap</u>, Être Handicap Information, No 122/123, January/February 2013.

In a number of countries, in particular the Scandinavian countries, the idea of disability is not defined at all to avoid any stigmatisation¹⁶ which could be brought about by a definition, occurrences which oppose the principles of participation, citizenship and equality of opportunities on which those countries' disability policies are based.

Lastly, the definition of disability may also vary within one country according to the objective – social or professional inclusion, special education, compensatory aid, support for those in need – and the administration in question – employment, social affairs, health, education, etc.¹⁷. A study carried out by the University of Brunel in 2004¹⁸ at the request of the Commission draws attention to the complexity of the issue:

'Applying a common definition of disability to the many policies of the EU Member States would undermine them and cause them to be misdirected. The necessity of using a plurality of definitions to ensure relevance raises a problem of coherence in disability policy'.

1.1.4. Towards a European Union definition?

In the light of the difficulties encountered in adopting a common definition at EU level, the above question remains a matter for the Member States. Nevertheless, although there is no single definition of disability at either EU or national levels, the definition put forward by the UN in 2006 has been used as a common reference ever since (see above).

By ratifying the United Nations Convention on the Rights of Persons with Disabilities at the end of 2010, the EU actually accepts the definition provided by the UN, which is based on human rights and the principle of non-discrimination. It reaffirms that position in the Disability Strategy 2010-2020¹⁹. Although the EU does not oblige the Member States to adopt a specific definition of disability, it must make sure that the definitions developed by the Member States are compliant with the prevailing ideas at international level. Every Member State has signed the Convention but the definition is only imposed on those, which have ratified it. Only Finland, Ireland and the Netherlands are exceptions.

1.2. Measuring disability in the European Union

To evaluate the number of people with disabilities and understand their situation in dealing with the difficulties that they face, it is essential to collect data even if it is difficult to create relevant indicators to follow its progression.

1.2.1. International surveys and national data

The UN started gathering data on the number of disabled people in the world in the 1980s. The data from the 1970s and 1980s can be found in 'Disability Statistics Compendium'²⁰ published in 1990 and in the 1993 Demographic Yearbook²¹. Typically they provide a collection of non-comparable data. Often using different definitions,

¹⁶ See in particular E. Goffman, <u>Stigmate. Les usages sociaux du handicap</u>, Paris, Les Éditions de Minuit, [1963], 1975.

¹⁷ The <u>MISSOC</u> is a useful resource for getting an idea of the variety of definitions and institutions active in each Member State.

¹⁸ <u>Definition of Disability in Europe: A Comparative Analysis</u>, A study prepared by Brunel University - Social security and social integration, European Commission, 2004.

¹⁹ European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM(2010) 636 final.

²⁰ <u>Disability Statistics Compendium</u>, United Nations, 1990.

²¹ 1993 Demographic Yearbook, United Nations, 1993.

countries sometimes provide absolute values and sometimes relative data based either on censuses or on sample surveys, for the whole population or only for adults of different age groups.

Other data may be obtained using international surveys in which respondents assess their own disability. However, self-assessment is, by definition, not objective and may reflect cultural or legal differences. What is more, it is difficult to distinguish between health problems and disabilities, which makes any comparison all the more difficult²².

1.2.2. EU surveys

The annual EU-SILC statistics (European Statistics on Income and Living Conditions) make up the main database²³.

Each year, Eurostat publishes a table of the key EU-SILC indicators (risk of poverty and/or social exclusion, material deprivation) using the Global Activity Limitation Indicator (GALI) as a measure of the situation of disabled people. Moreover, the Commission works with the Academic Network of European Disability Experts (ANED²⁴) to analyse the EU-SILC data on the situation of disabled people in the Member States. The ANED produces reports on specific topics such as access to education²⁵, policies to help people with disabilities to live independently²⁶, consumer protection in the case of disability²⁷ or social protection of disabled people²⁸. It also evaluates the progress made towards the targets of the Europe 2020 Strategy²⁹ (the EU strategy for smart, sustainable and inclusive growth) as regards disability by focusing on the key employment, education and poverty-reduction targets. In parallel, the Commission produces national reports as part of the European Semester process³⁰. The ANED manages the Commission's online database (DOTCOM³¹) following the disability policies and initiatives of the Member States, candidate countries and other associated countries.

Other specific survey modules have been created to collect data related to disability, such as:

²² C. Barral, D. Chiriascescu, <u>Analyzing disability assessment procedures in the light of the UN Convention on the Rights of Persons with Disabilities: A proposed methodological guide</u>, ALTER - European Journal of Disability Research, Volume 9, Issue 1, January-March 2015.

²³The 'GALI' (Global Activity Limitation Indicator) question measures the proportion of people who claim to have been, 'for at least the past six months, [...] limited because of a health problem in activities people usually do'.

²⁴See: <u>The Academic Network of European Disability Experts.</u>

²⁵ Synthesis report on inclusive education for young disabled people in Europe: trends, issues and challenges, ANED, April 2011.

²⁶ Implementation of policies supporting independent living for disabled people in Europe: synthesis report, ANED, November 2009.

²⁷ The Protection of Consumers with Disabilities in the European Union: Persons with Disabilities as Active Participants in the Internal Market, ANED, December 2012.

²⁸ Social protection for disabled people in Europe: synthesis report, ANED, 2016.

²⁹ Europe 2020 in a nutshell, European Commission, last updated: 18 August 2016.

³⁰ European Semester, European Council, last revised on 24 January 2017.

³¹ DOTCOM: the Disability Online Tool of the Commission is constructed from a large database of information on national laws, policies, strategies and initiatives in the Member States of the European Union, its Candidate Countries and other associated countries.

- The ad hoc module of the 2011 Labour Force Survey³² examines the situation of disabled people in the labour market compared with people without disabilities for 15-64 year-olds living in private homes. In the survey, disabled people are those who claim to have difficulties performing some basic activities such as seeing, hearing, walking or remembering;
- The European Health Interview Survey (EHIS)³³ gathers data every five years on the level of functioning and activity limitations of the whole population and information on health condition, health determinants and use of healthcare;
- The European Survey on Health and Social Integration³⁴ of 2012-2013 collected data on the barriers met by people with a health problem or difficulties performing certain basic activities which prevent them from participating various aspects of daily life. That survey is the source of the most complete European information on the barriers to participation of people with a health problem or difficulty performing basic activities.

Although the surveys are a fertile source of information, they do not gather information on people living in institutions (in particular elderly people and disabled children) or on children in the household (the EU-SILC survey starts from the age of 16).

To harmonise disability data collection, the Commission hopes to introduce the GALI as a 'basic' social variable in all surveys related to disability. Negotiations are underway between Eurostat and the Member States to introduce that disability variable in the Labour Force Survey once every two years, thereby creating a reliable tool to monitor employment among disabled people³⁵. The SILC 2017 module on children should also include a projection of the probability of future disability (GALI variable adapted to children) to eliminate the knowledge deficit regarding disabled children in households.

1.2.3. Living with a disability in Europe today: some statistics

Bearing in mind that there is no 'harmonised' definition of 'disability' in the EU, and taking into account the wide variety of statistical surveys in terms of both the questions asked and the population used, it is impossible to make a complete statistical assessment of disability in Europe.

According to the data collected by Eurostat in the 2011 Labour Force Survey ³⁶, 44 million people between the ages of 15 and 64 (14% of the age group) claimed to suffer from a difficulty performing a basic activity in the EU28³⁷. In France, Luxembourg, Austria and Finland, more than 20% of that group claimed to have such difficulties. In contrast, less than 10% of people aged between 15 and 64 claimed to have difficulties in performing basic activities in Cyprus, Italy, the Czech Republic, Spain, Malta, Greece, with the lowest percentage having been recorded in Ireland (5.3%).

³⁴ <u>Disability statistics background - European health and social integration survey</u>, Eurostat, Statistics explained, November 2015.

³²Disability statistics - barriers to social integration, Eurostat, November 2015.

³³ European Health Interview Survey (EHIS).

³⁵ European Commission, <u>Progress Report on the implementation of the European Disability Strategy</u> (2010-2020), 2017.

³⁶ <u>Disability statistics background - European health and social integration survey</u>, Eurostat, Statistics explained, November 2015.

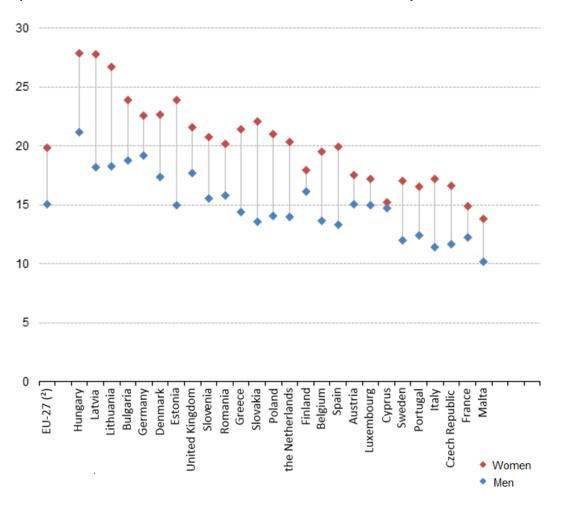
³⁷ Fewer than 1 in 2 disabled adults were in employment in the EU28 in 2011, Eurostat, News Release, 2 December 2014.

Moreover, some 35 million people aged between 15 and 64 (11%) claimed to have a disability in the context of employment in the same 2011 survey.

To improve the statistics on people with a disability in Europe today, the use of information from the EHIS offers the advantage of covering not only the 15-64 age group, but also 65 and over (the prevalence of disability being higher among older people).

According to the EHIS survey, 70 million people aged 15 and older claimed to be suffering from a disability, i.e. 17.6%, of the population in the EU27. That is 2.3 percentage points higher for women (19.9%) than for men (15.1%). This means that almost three fifths (58.4%) of disabled people over the age of 15 were women. Without exception, a larger proportion of women than men reported a disability in all the Member States for which the information was available in 2012 (see Graph 1).

Graph 1 – Share of women and men who claimed to have a disability in 2012



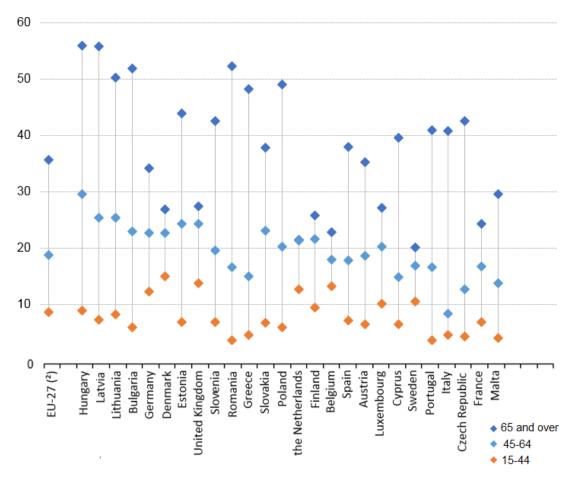
Reference: Eurostat, EHIS, 2012.

Data not available for Croatia and Ireland.

Across the Member States, the percentage of disabled people varied from 12% in Malta to a little more than double that in Hungary, where almost one quarter (24.8%) of people over the age of 15 claimed to have a disability.

Elderly people (65 years and older) accounted for more than two fifths (42.2%) of all disabled people over the age of 15 in the EU-27 in 2012, while over a third of disabled people were aged between 45 and 64 (35.5 %) and the remaining fifth was aged between 15 and 44 (22.3 %, see Graph 2).

Graph 2 – Prevalence of disability by age of the respondents in 2012



Reference: Eurostat, EHIS, 2012.

Data not available for Croatia and Ireland.

A large majority of Member States had similar results regarding family composition: the prevalence of disability is lower in households with children than in those with just one person or couples without children. The following countries are an exception: Belgium, France, Lithuania, the Netherlands, the United Kingdom and Sweden (see Graph 3).

45 40 35 30 25 20 15 10 5 0 Romania Greece Bulgaria Slovakia Poland Finland Belgium Austria Cyprus EU-27 (²) Estonia Slovenia Portugal ithuania. United Kingdom the Netherlands Luxembourg Sweden Germany Denmark Czech Republic × Single person ◆ Other

Graph 3 – Prevalence of disability according to family composition in 2012³⁸

Reference: Eurostat, EHIS, 2012.

Data not available for Croatia and Ireland.

×Couple without children

Couple with children

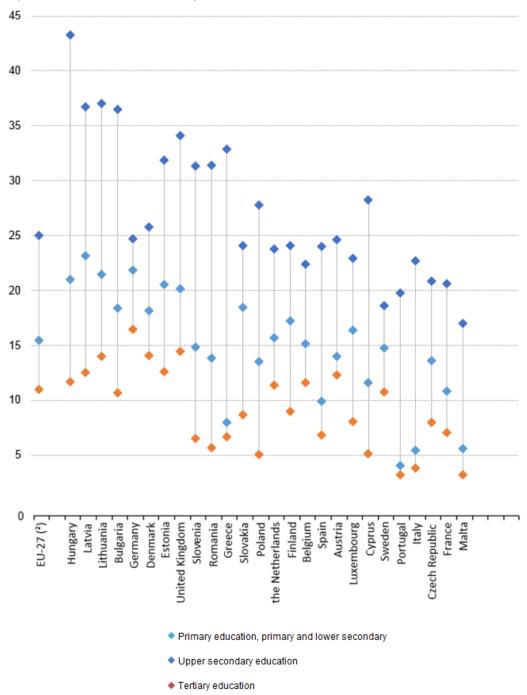
Single parent

× At least one parent with children and one other person

³⁸ The 'other' category includes, for example, households with several generations (with or without children under the age of 25) or households of people without family ties.

Every Member State had the same model of disability prevalence in relation to level of education. Disability was more common among those with the lowest level of education than among those with the highest qualifications (see graph 4).

Graph 4 - Prevalence of disability in relation to level of education



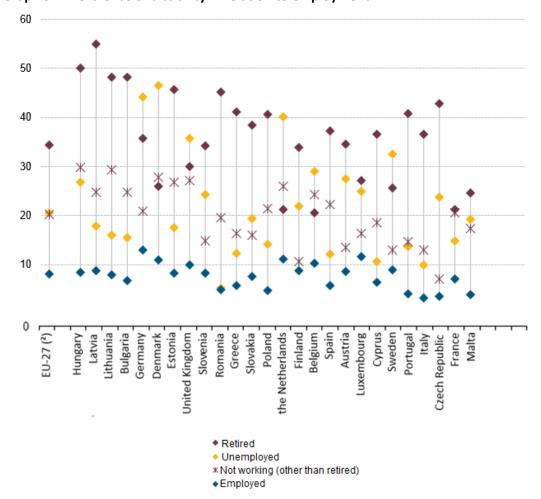
Reference: Eurostat, EHIS, 2012.

Data not available for Croatia and Ireland.

The fact that disability is more common among people in the less qualified groups may reflect, in particular: the barriers which young disabled people meet to gaining access to higher education; the increased risk of disability arising from accidents and occupational diseases for people with a lower level of education; the increased risk of disability

originating from poor health conditions such as obesity³⁹ and smoking-related problems⁴⁰ which correlate with a lower level of education.

Almost half of all disabled people (47.3%) in the EU-27 were retired, while a fifth (20.3%) did not work for other reasons – e.g. school pupils, students, people caring for others (children and/or elderly family members) (see Graph 5). Almost a quarter of disabled people (22.7%) worked, while one in ten were unemployed (9.7%). As such, slightly lower than a third (32.4%) of all disabled people over the age of 15 were on the labour market (with or without employment).



Graph 5 - Prevalence of disability in relation to employment

Reference: Eurostat, EHIS, 2012. Data not available for Croatia and Ireland.

2. Premises of an EU disability policy

Alongside and in support of national policies, the EU intends to fight all forms of discrimination. In this context, and to improve the situation of disabled people, it has introduced a series of initiatives, programmes and strategies over a number of decades.

³⁹ Obésité et milieux sociaux, Observatoire des inégalités, 24 April 2013.

⁴⁰ D. Bricard *et alii*, <u>L'évolution des inégalités sociales de tabagisme au cours du cycle de vie : une analyse selon le sexe et la génération</u>, Économie et Statistique, No 475-476, 2015.

2.1. First initiatives

Disability policy took a European Union dimension with the first action programme in 1974⁴¹, followed by the HELIOS⁴² and HORIZON⁴³ initiatives and, later, the EQUAL⁴⁴ initiative. Those programmes gave rise to information exchange and transnational cooperation in the different areas of economic and social integration, independent living, work, education or equality of opportunity for disabled people.

2.2. 'Equal opportunities for people with disabilities'

In 1993, the Commission published a report on the measures, which needed to be taken at Community level to improve accessibility of public transport for people with reduced mobility. In 1994, a White Paper entitled 'Action for the future' addressed social integration and independence of disabled people, and the 'European guide of good practice: towards equal opportunities for disabled people', a product of the HELIOS II programme, was released in December 1996.

In 1996, the Commission published a communication entitled 'Equality of Opportunity for People with Disabilities - A New Community Disability Strategy 1996'⁴⁵. It is based, above all, on the UN's 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 1993'⁴⁶, which emphasise environmental barriers⁴⁷ over functional limitations with a view to equal participation of disabled people in society. Two organisations played a leading role in establishing that first political strategy: the interservice group on disability of the European Commission⁴⁸ and the intergroup on disability created in 1980 at the European Parliament (see below).

Article 13 of the Treaty of Amsterdam of 1997 (see below) contributed to the promotion of equal rights for disabled people in the EU and paved the way for a genuine disability policy based on non-discrimination. In November 2000, the Council adopted a directive, which created a general framework to promote equal treatment in employment and work⁴⁹. It recognised that the failure to provide 'reasonable accommodation' in the workplace could constitute discrimination. As regards transport, the Member States adopted a directive in 2001 (after nine years of debate) which obliges bus manufacturers to provide access for people with reduced mobility⁵⁰.

⁴¹ Council resolution of 21 January 1974 concerning a social action programme.

⁴² The HELIOS I (1988-1992) and HELIOS II (1993-1996) programmes supported Member-State cooperation, in particular the exchange of information and good practices as regards economic and social integration, equality of opportunity and independent living of disabled people.

⁴³ In 1990, the HORIZON programme was adopted to improve the conditions for access to work of disabled people and other disadvantaged groups.

⁴⁴ The community initiative <u>EQUAL</u> was funded by the European Social Fund (ESF) and co-funded by the Member States over the course of the 2000-2006 programming period. The initiative focused on supporting innovative transnational projects designed to combat discrimination and disadvantages on the labour market.

⁴⁵ COM(96) 0406 final, 30 July 1996.

⁴⁶ Standard Rules on the Equalization of Opportunities for Persons with Disabilities, United Nations, 1993.

⁴⁷ Examples of <u>'environmental obstacles'</u>, Disability and Development, Agence française du développement.

⁴⁸ The purpose of this group is to establish audit and informational tools for the Commission services.

⁴⁹ Directive 2000/78/EC.

⁵⁰ Directive 2001/85/EC.

An action programme to combat discrimination (2001-2006)⁵¹ was adopted to stimulate the introduction of specific measures to tackle discrimination and was designed to complement the work of the EU and its Member States, particularly their legislative work.

As an additional step, in May 2001 the European Commissioner for Social Affairs called on the European Council to dedicate the year 2003 to disabled people (see box below).

2003 - European Year of People with Disabilities

The year 2003 was named 'European Year of People with Disabilities' (EYPD) to highlight and raise public awareness of the situation faced by disabled people. To this end, the EU set aside a budget of EUR 12 million to stimulate initiatives and launched an action plan entitled Equal opportunities for people with disabilities: a European Action Plan (2004-2010)⁵². It sought to ensure that disability issues were incorporated into all EU policies that may affect the lives of disabled people. The EYPD sought, in particular, to raise awareness of the rights of people with disabilities to protection against discrimination; to foster reflection on and discussion of the measures needed to promote equal opportunities for disabled people in Europe; to develop experience exchanges regarding good practice and effective strategies devised at local, national and European level; to improve communication on disability; to increase the attention paid to the rights of disabled children and young people to equality in education, etc. Among the main actions taken that year, of particular note are the introduction of a specific information and promotion campaign entitled 'Get on board', for which a campaign bus travelled throughout the EU providing disabled people and disability organisations with a means of promoting their activities, highly visible media and the creation of a company participation programme to ensure that businesses promote employment and training opportunities for disabled people.

2.3. Including disability in EU charters and treaties

As the EU paid closer attention to the situation of disabled people, the question of the legal basis on which it would introduce a genuine EU disability policy became more and more important⁵³.

In 1989, Article 26 of the Charter of the Fundamental Social Rights of Workers⁵⁴ recognised the right of every disabled person to professional and social integration:

'All disabled persons, whatever the origin and nature of their disablement, must be entitled to additional concrete measures aimed at improving their social and professional integration. These measures must concern, in particular, according to the capacities of the beneficiaries, vocational training, ergonomics, accessibility, mobility, means of transport and housing. '

With immense pressure from non-governmental organisations and associations, the issue of disability was written into the 1997 Treaty of Amsterdam⁵⁵. Article 13 stipulates that:

⁵¹ Council Decision 2000/750/EC of 27 November 2000.

⁵² COM(2003) 650 final.

⁵³ Étude administrative comparée sur les dispositifs de compensation du handicap en Europe — Rapport thématique sur le handicap en Europe, Inspection Générale des Affaires Sociales, September 2003.

⁵⁴ Community Charter of the Fundamental Social Rights of Workers, 1989.

⁵⁵ Treaty of Amsterdam amending the Treaty on European Union, the Treaties establishing the European Communities and certain related acts, 1997.

'Without prejudice to the other provisions of this Treaty and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission and after consulting the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation'.

The inclusion of disability in the Treaty of Amsterdam gave the EU a new competence enabling it to combat discrimination against disabled people. It is worth noting that the legal recognition of the rights of disabled people to full integration into society does not, however, mean that all disabled people enjoy the new rights in practice.

Moreover, a provision on the integration of disabled people was written into Article 26 of the Charter of Fundamental Rights of the European Union⁵⁶, proclaimed in Nice in December 2000, which stated that:

'The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community'.

The measures taken in the Member States to guarantee compliance with the Charter must be guided by the need to enable disabled people to lead a normal life and be socially integrated on an equal level with others. Having come into effect in 2009, the Treaty of Lisbon attributed the same legal value to the Charter as to the Treaties.

Lastly, by ratifying the UNCRPD in 2010, the EU associated itself with the efforts agreed at international level to guarantee the fundamental rights of disabled people.

3. The European Disability Strategy 2010-2020

3.1. A European strategy for 10 years

To continue its activities, the EU published a new 'European Disability Strategy 2010-2020'⁵⁷ to enable disabled people to enjoy their rights in full and to participate in society and the economy on an equal level with others. It draws on the UNCRPD and also complements the Europe Strategy 2020⁵⁸ and the Charter of Fundamental Rights of the European Union. The action plan connected with the European Strategy 2010-2020 covers eight areas: accessibility, participation, equality, employment, education, social protection and inclusion, health and external actions⁵⁹.

3.2. Related initiatives

In relation to the European Strategy 2010-2020, the Commission supports a number of initiatives and actions designed to assist disabled people. Of particular note are the following initiatives:

⁵⁶ Charter of Fundamental Rights of the European Union, 2000.

⁵⁷ A Renewed Commitment to a Barrier-Free Europe (COM(2010) 636 final).

⁵⁸ Europe 2020 in a nutshell, European Commission, last updated: 18 August 2016.

⁵⁹ <u>People with disabilities have equal rights - The European Disability Strategy 2010-2020</u>, European Commission, 2010.

- On 3 December each year, the Commission, together with the European Disabilities Forum⁶⁰, organises a conference to mark the European Day of Persons with Disabilities. The conference brings together decision-makers, people with and without disabilities, academic experts, the media and other stakeholders. They are part of the EU's efforts to highlight the issue of disability in accordance with its disability strategy;
- To encourage cities to improve accessibility, the Commission presents annual awards to the most accessible cities⁶¹;
- A European disability card scheme⁶² is being piloted in eight Member States and should enable disabled people to travel more easily in those countries;
- The provisions of the Erasmus+ programme⁶³ promote mobility of disabled students, and the increased attention to disability in EU policy regarding external action has been recognised by the UN Committee on the Rights of Persons with Disabilities in its recommendations to the EU;
- Disabled people also benefit from the Directive on cross-border healthcare⁶⁴;
- The Directive on internet accessibility⁶⁵, which seeks to make the websites of public sector bodies accessible to everybody, and the proposal for a Directive on the accessibility of goods and services⁶⁶ (see box below) are also key aspects in the promotion of accessibility for disabled people.

Accessibility of goods and services

The European Disability Strategy 2010-2020 makes accessibility ones of its priorities. Although the Commission sought to develop, on a voluntary basis, common standards for accessibility in the specific areas of information technology and infrastructure, they proved difficult to introduce in the light of the different approaches taken by the Member States as regards the promotion of accessibility.

The proposal for a Directive on accessibility of goods and services is designed to help eliminate the barriers in the Member States in an effort to improve the functioning of the internal market as regards accessibility of goods and services. Announced in January 2011, and scheduled for the end of 2012, the Commission's proposal finally saw the light of day on 2 December 2015.

The proposal established the list of what needed to be made accessible to everybody (computers, telephones, television, media, transport, banking services, e-books and e-commerce) without imposing detailed technical solutions. According to the Commission, its proposal for a Directive is designed to reduce the barriers for disabled people to education, employment and participation in society, and should contribute to greater social inclusion in the EU.

⁶¹ Access City Award, European Commission.

⁶⁰ European Disability Forum.

⁶² European Disability Card, European Commission.

⁶³ Erasmus +, Programme Guide, European Commission, 2016.

⁶⁴ <u>Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare.</u>

⁶⁵ <u>Directive (EU) 2016/2102</u> of the European Parliament and of the Council of 26 October 2016 on the accessibility of the websites and mobile applications of public sector bodies.

⁶⁶ Proposal for a Directive of the European Parliament and of the Council on the approximation of the laws, regulations and administrative provisions of the Member States as regards the accessibility requirements for products and services, COM(2015) 615, 2015/0278(COD).

3.3. The European Parliament's role

Since the start of the 1980s, Parliament has given priority to combating all forms of discrimination against disabled people. On the strength of the work by the Disability Intergroup⁶⁷, the MEPs adopted a number of decisions concerning the integration of disabled people and the acknowledgement and protection of their rights, calling on the Member States and the Commission to develop norms and regulations in the interests of disabled people. The establishment of rights to a decent income, social protection and social security are high on the intergroup's agenda.

When it adopted a resolution on the rights of disabled people in December 1996⁶⁸, Parliament called on the Member States to include a clause on non-discrimination on grounds of disability when the Treaty on European Union was revised, to enact a new legal basis for social programmes, to introduce non-discrimination measures and to treat the rights of disabled people as a civil rights issue. It also called on the Commission to present a new action programme on equalisation of opportunities for disabled people, and to carry out censuses in all the Member States to improve the statistics on the causes or extent of disabilities. What is more, it called on the EU institutions and Member States to review their access and employment policies.

In March 1998, the European Parliament advocated the introduction of a European parking card⁶⁹ intended for disabled people and valid throughout the EU.

As a further initiative, on 5 June 2013, the presidents of the five main political groups of the European Parliament adopted a declaration⁷⁰ in which they proposed six commitments to support the rights of disabled people in Europe. The MEPs pledged, in particular, to make their informational documents more accessible so that disabled people could participate under the same conditions as everybody else in the 2014 European elections.

In December 2013, Parliament adopted a resolution on disabled women⁷¹ in which it recalled that they were disadvantaged in a number of ways. They experienced difficulties in gaining access to adequate housing, healthcare, public transport, education, vocational training and employment, were victims of inequality in access to credit and rarely participated in decision-making processes. Parliament called for the introduction of strategies, legislative initiatives and policies to guarantee non-discrimination and equal opportunities for disabled women.

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⁶⁷ When it was created in 1980 by D. Prag (United Kingdom, EPP), it was called the 'All Party Disablement Group'. The Disability Intergroup is a group of MEPs, which works in the European Parliament on disability policy. The intergroup works to support disabled people and meets regularly in Strasbourg to discuss priority issues. It decides which follow-up actions to take: to address parliamentary questions to the European Commission, table amendments to reports issued by the European Parliament on EU policies and programmes which affect disabled people. The intergroup works closely with the European Disabilities Forum (EDF-FEPH).

⁶⁸ Resolution of the European Parliament of 13 December 1996 on the rights of disabled people, A4-0391/96, Official Journal No C 020 of 20 January 1997.

⁶⁹ Council Recommendation of 4 June 1998 on a parking card for people with disabilities (98/376/CE).

⁷⁰ Final Declaration, Meeting of the Presidents of the Political Groups of the European Parliament with the European Disability Forum, Brussels, 5 June 2013.

⁷¹ European Parliament resolution of 11 December 2013 on women with disabilities, 2013/2065(INI).

In its resolution on an 'Integrated Approach to Sport Policy: good governance, accessibility and integrity'⁷² adopted in February 2017, Parliament stressed that disabled people should have equal access to all sports facilities and called on the Member States to introduce sports programmes for disabled people in schools and universities.

⁷² European Parliament resolution of 2 February 2017 on an integrated approach to Sport Policy: good governance, accessibility and integrity (2016/2143(INI)).

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More than 70 million people in the EU, close to one in six, have a disability. Many of them encounter difficulties performing simple daily tasks, pursuing studies and getting a job. That is why, alongside and in support of Member State policies, the EU has committed to combating all forms of discrimination to which disabled people are particularly vulnerable.

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