Disability statistics introduced

Statistics Explained

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Disability is a complex, evolving and multi-dimensional concept. Disabilities impact on people's lives in many areas, for example in terms of: mobility and the use of transport equipment; access to buildings; participation in education and training, the labour market and leisure pursuits; social contacts and economic independence.

This introductory article explains the background to the rights of people with disabilities and outlines various models of disability. It then looks at some of the issues related to measuring disability for statistical purposes and summarises the various European Union (EU) sources of disability statistics.

This article provides an introduction to a number of statistical and methodological articles which make up an online publication on disability statistics .

Background

United Nations Convention on the rights of persons with disabilities

The United Nations (UN) Convention on the Rights of People with Disabilities (UNCRPD) was adopted in December 2006, opened for signature in March 2007, and entered into force in May 2008.

The Convention is intended as a human rights instrument, with an explicit social development dimension. Its purpose is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'; it also sets out a code of implementation.

In Article 1, the Convention defines persons with disabilities as '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'.

The Convention foresees that countries are to guarantee that persons with disabilities enjoy their inherent right to life on an equal basis with others (Article 10), regardless of age and gender (Articles 6 and 7).

On the fundamental issue of accessibility (Article 9), the Convention requires countries to identify and eliminate obstacles and barriers and ensure that persons with disabilities can access their environment, transportation, public facilities and services, and information and communications technologies.

Persons with disabilities must be able to live independently, to be included in the community, to choose where and with whom to live and to have access to in-home, residential and community support services (Article 19). Signatories should foster personal mobility and independence (Article 20) and recognise the right of persons with disabilities to an adequate standard of living and social protection (Article 28).

The Convention also requires persons with disabilities to be afforded equal access to education and training (Article 24), equal rights to work and to gain a living without discrimination (Article 27), to participate in political and public life (Article 29) and to participate in cultural life, recreation, leisure and sport (Article 30). Furthermore, the Convention specifies that persons with disabilities have the right to the highest attainable standard of health without discrimination and to receive the health services needed because of their disabilities and not to be discriminated against in the provision of health insurance (Article 25).

As well as protecting the rights of disabled persons in specified areas, the Convention also requires stereotypes and prejudices to be combatted and to the awareness of the capabilities of persons with disabilities to be promoted (Article 8).

The Convention is the first international, legally binding instrument setting minimum standards for rights of people with disabilities. It was also the first human rights convention to which the EU has become a party: the Council adopted the Decision for the conclusion of the Convention on 26 November 2009 and the Convention entered into force in the EU on 22 January 2011. Furthermore, all EU Member States have signed the Convention although, at the time of writing, Ireland, the Netherlands and Finland have not yet ratified it. A total of 25 EU Member States (all except Ireland, the Netherlands, Poland) have also signed or acceded to the Optional Protocol , 22 of which (not the Czech Republic, Romania or Finland) have ratified it. The core elements of the UN Convention are reflected in the European Disability Strategy 2010–20 .

EU Charter on Fundamental Rights

The EU promotes the active inclusion and full participation of disabled people in society, in line with the EU human rights approach to disability issues. The Charter of Fundamental Rights of the EU brings together in a single document a set of fundamental rights that should be protected in the EU. The Charter contains rights and freedoms under six titles: dignity, freedoms, equality, solidarity, citizens' rights, and justice. It was initially proclaimed in December 2000 without any binding legal effect and subsequently became legally binding with the entry into force of the Lisbon Treaty amendment to the Treaty on European Union , in December 2009. The EU's Charter of Fundamental Rights prohibits discrimination on the ground of disability and recognises the right of disabled people to integration.

European disability strategy 2010–20

The European Disability Strategy 2010–20 , adopted in 2010, builds on the UN's Convention and takes into account the experience of the Disability Action Plan (2003–10) . The strategy's objectives cover eight priority areas.

1. Accessibility: make goods and services accessible to people with disabilities and promote the market for assistive devices.
2. Participation: ensure that people with disabilities enjoy all benefits of EU citizenship; remove barriers to equal participation in public life and leisure activities; promote the provision of quality community-based services.
3. Equality: combat discrimination based on disability and promote equal opportunities.
4. Employment: raise significantly the share of persons with disabilities working in the open labour market.
5. Education and training: promote inclusive education and lifelong learning for students and pupils with disabilities.
6. Social protection: promote decent living conditions, combat poverty and social exclusion.
7. Health: promote equal access to health services and related facilities.
8. External action: promote the rights of people with disabilities in the EU's enlargement and international development programmes.

Data for policy needs

As can be seen from the broad nature of the UN Convention and the EU's disability strategy, policy issues related to disability concern the social integration of people with disabilities in all aspects of life.

The functional status of people needs to be taken into account in many policy areas, such as health, social protection, housing, transport, culture, education and employment. Policy development in these areas can benefit from reliable data on the functional status of the population.

Disability models

Medical and social models

Traditionally, two main models of disability existed, namely the medical and the social model.

The medical model focuses on a health condition — a disease, illness, injury or health problem — of an individual which directly causes the disability of that individual, potentially impacting on that individual's quality of life. As a consequence, medical intervention may be required to identify and treat the disability, and/or to maintain or increase functioning.

The social model focuses on socially-created barriers. These barriers may be physical or concern attitudes and other social features that do not accommodate the variety of abilities of the population.

These two models take a different perspective of the interaction between the health condition of an individual and the environment in which that individual lives: the medical one focuses on the individual; the social one on the barriers thrown up, intentionally or otherwise, by the environment.

Biopsychosocial model — the basis for the ICF

The International classification of functioning, disability and health (ICF) is a multipurpose classification, published by the World Health Organisation , intended for a wide range of uses in different sectors. Rather than being a classification of disability, it is an all-encompassing classification of functioning/disability and health that helps to describe:

- **body function and structure;**
- what a person with a health condition can do in a standard environment, in other words their level of capacity in relation to **activities** ;
- what a person can actually do in their usual environment, in other words their level of performance in relation to **participation** .

Body functions are physiological functions of body systems (including psychological functions). Body structures are anatomical parts of the body such as organs, limbs and their components. Impairments are problems in body function or structure such as a significant deviation or loss. Activity is the execution of a task or action by an individual. Activity limitations are difficulties an individual may have in executing activities. Participation is involvement in a life situation. Participation restrictions (or barriers) are problems an individual may experience in involvement in life situations.

As a result, and following the ICF model, the term **functioning** is used to refer to body functions, activities and participation and the term **disability** is used to refer to impairments, activity limitations and participation restrictions.

The ICF is based on what might be called a biopsychological model: a biopsychological model combines biological, psychological (thought, emotion and behaviour), and social (economical, environmental and cultural) factors.

The ICF model of disability builds on the three basic concepts — body function and structure, activities and participation — integrating the medical side of health conditions as well as what it refers to as contextual factors relating to the individual (personal factors) and society (environmental factors). Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives and include, for example, social attitudes, architectural characteristics, legal and social structures, climate and the physical environment. Personal factors include: sex, age, social background, education, profession, ability to cope, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual. A graphical representation of the model is shown below.
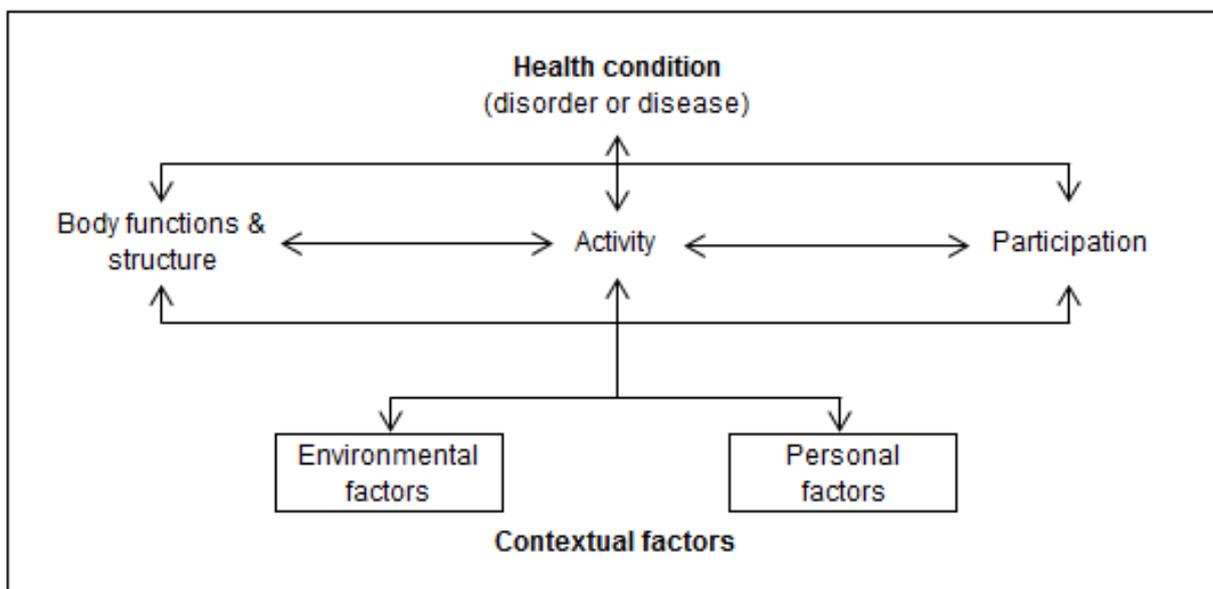
Source: Towards a Common Language for Functioning, Disability and Health, WHO 2002

Diagram 1: A representation of the model of disability that is the basis for the ICFSource: Towards a Common Language for Functioning, Disability and Health, WHO 2002

How data on functioning and disability can be collected

Aspects of functioning and disability

Based on the approach presented in the ICF, the measurement of human functioning/disability can be approached from a number of perspectives.

One approach is to look at impairments, in other words to identify what physical or mental conditions people have that impact their body function or structure.

Equally, functional limitations can be measured, by identifying what activities people can or cannot do.

A broader approach is to look at the issue of social integration and evaluate what people actually do in various aspects of life, in other words their performance. From this starting point, the barriers (or restrictions) to participation can be identified; in turn these barriers can be linked to disabilities — such as restrictive health conditions or activity limitations — or to environmental or personal factors.

As is clear from the ICF model, when looking at functioning and disability in the framework of social integration, it is important to be aware of the contextual factors. For example, the extent to which people wish to participate in specific areas varies and social integration may also be influenced by personal/family and financial considerations. Equally, the opportunities for participation may vary, for example because of conditions in education systems and the labour market, or because of the extent of the supply of services, such as the availability of transport services or leisure activities. As such, measures of participation look at what people do and what they want to do, in reference to their own specific context.

Types of surveys used for data collection

As is clear from the above, there is no fixed definition of disability and as such there is not a single method to measure it. The definition or definitions that are applied for statistical purposes depend to a large extent on the number of questions that can be asked about impairments, limitations and barriers to participation.

At the time of writing, EU statistics on disability have been collected from a variety of different sources — see Table 1.

	European health and social integration survey (EHSIS)	European health interview survey (EHIS)	Statistics on income and living conditions (SILC)	Ad hoc module on employment of disabled people in the labour force survey (LFS)
Main topics covered	Disability as defined by the UN Convention	Health status, health determinants and health care use	Income, social inclusion and living conditions	Employment of disabled people
Legal basis	No	Yes	Yes	Yes
Periodicity	Once (2012)	5-yearly	Annual	Irregular (2002 and 2011)
Limitations in usual activities caused by a health problem	Yes	Yes	Yes	
Difficulties in carrying out basic activities	Yes	Yes		Yes
Difficulties in performing personal care activities	Yes	Yes (persons aged 65+)		
Difficulties in performing household care activities	Yes	Yes (persons aged 65+)		
Participation restriction linked to a health condition and/or a basic activity difficulty	Yes			
Limitation in work caused by health problems and/or difficulties in basic activities	Yes			Yes

Table 1: Overview of data sources for EU statistics on disability

In broad data collection exercises, such as the European health interview survey (EHIS) conducted in two waves between 2006 and 2009 and between 2013 and 2015 or the annual statistics on income and living conditions (SILC) , only a (very) limited number of questions could be asked, otherwise the data collection would be overburdened. As a result only some aspects of disability can be surveyed.

In a dedicated module of a larger survey, such as the ad hoc module on employment of disabled people in the 2011 labour force survey (LFS) , or in a dedicated survey, such as the European health and social integration survey (EHSIS) conducted in 2012, it is possible to collect a wider range of data from a higher number of questions. Consequently, a more sophisticated and complete measurement of disability can be undertaken.

Definitions used

General definition from the UN Convention

In Article 1, the UN Convention defines persons with disabilities as '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'.

In its April 2015 note on ' Improvement of disability data and statistics: objectives and challenges ', the UN secretariat of the Convention on the Rights of Persons with disabilities noted that 'disability is a complex and multidimensional issue that poses a number of challenges for data collection and measurement. The lack of a uniform definition and understanding of disability among countries and the application of non-comparable methodologies in the measurement and collection of data and statistics mean data are not consistent or comparable among countries'.

Definitions in statistics

Prior to the development of EU-wide statistics on disability, national definitions varied, as they were often used primarily for determining benefit entitlements or for specific policies.

Dedicated surveys/modules   Eurostat currently disseminates data on the prevalence of disability from two sources, the 2011 LFS ad hoc module and the EHSIS. In these surveys the following definitions were used:

- 2011 LFS ad hoc module on employment of disabled people — people reporting a basic activity difficulty;

- EHSIS — people facing barriers to participation, owing to a long-standing health problem and/or a basic activity difficulty.

The basic difference between these two definitions is that:

- for the 2011 LFS ad hoc module on employment of disabled people the existence of a basic activity difficulty resulted in a respondent being considered to be disabled;

- in the EHSIS not only did a person need to have a long-standing health problem and/or a basic activity difficulty, but this also had to be a barrier to participation in at least one of the 10 selected life areas (such as, transportation, education and training, or leisure pursuits).

In addition, the 2011 LFS ad hoc module looked specifically at barriers to employment and looked at people who were disabled in the sense that they were limited in the work they can do because of a long-standing health problem and/or a basic activity difficulty. This definition was closer to that used in the EHSIS as it associated the limitation in participation to a long-standing health problem and/or a basic activity difficulty; however, it only looked at one life area, namely employment (the labour market).

Other surveys   In addition, two other sources — the EHIS and SILC — collect more limited data on some aspects of disability and the key disability related indicators in both of these data collection exercises are:

- people with a long-standing health problem (both EHIS and SILC);

- people with some (or severe) activity limitation due to a (long-standing) health problem (both EHIS and SILC);

- physical and sensorial functioning (EHIS);

- performance of activities of daily living (EHIS, only for older persons);

- performance of instrumental activities of daily living (EHIS, only for older persons).

In practice, the information on the level of activity limitation is used for the dissemination of SILC data in relation to disability.

Other challenges to data collection

EU disability statistics are currently compiled from household surveys and these normally exclude people living in collective households and institutions, thereby excluding a part of the population where it may be expected that the prevalence of disability is high.

Another issue facing EU disability statistics is the coverage of disabled people of all ages, as most household surveys have an age threshold such that persons aged less than 15 or 16 are excluded.

As well as the difficulty of defining disability, the April 2015 note on 'Improvement of disability data and statistics: objectives and challenges', also outlined a number of challenges to data collection, including:

- Disability statistics often rely on self-reporting of disabilities and in such cases many persons may perceive their situation as not severe enough to be considered a disability even though their daily activities are limited. In such cases, disability statistics only cover significant or severe disabilities.

- The word 'disability' may carry negative connotations and respondents may not wish to identify themselves as disabled, again leading to under-reporting.

- The relation between disability and a diagnosable medical condition may also lead to problems, for example if people do not know their diagnosis. Furthermore, medical diagnosis may bias collected data if the availability of diagnosis is correlated with certain socio-economic characteristics or access to health services.

See also

Online publications

- Disability statistics
- Health in the European Union – facts and figures

Background articles related to the methodology of disability statistics

- Disability statistics background - Labour force survey - overview
- European health and social integration survey
- European health interview survey - methodology
- Health variables in SILC - methodology

Further Eurostat information

Database

- Disability (hlthdsb)

Dedicated section

- Health
- Disability

Methodology / Metadata

- Background articles concerning the methodology for the production of disability statistics in the EU
- European health and social integration survey (EHSIS) (ESMS metadata file — hlthdsbprveesms)
- European health interview survey (EHIS) (ESMS metadata file — hlthdetesms)
- Income and living conditions (ilc) (ESMS metadata file — ilcesms)
- Prevalence of disability (source LFS) (ESMS metadata file — hlthdsbprvesms)

External links

- Academic Network of Experts on Disability (ANED)
- European Commission — Directorate-General for Employment, Social Affairs and Inclusion — Social protection and social inclusion — EU social indicators
- European Commission — Directorate-General for Employment, Social Affairs and Inclusion — Social protection and social inclusion — Persons with disabilities
- European Commission — Directorate-General for Health and Food Safety — Public health — ECHI — European Core Health Indicators
- European Commission — Directorate-General for Health and Food Safety — Public health — Indicators — Policy
- European Union Agency for Fundamental Rights
- People with disabilities
- United Nations enable — rights and dignity of persons with disabilities
- Convention on the Rights of Persons with Disabilities

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