# IDEE INDICATORS OF DISABILITY EQUALITY IN EUROPE Feasibility study An evaluative report on the feasibility of using existing data sources

Ву

S. Grammenos CESEP ASBL

December 2009





# CONTENTS

INTRO	DUCT	FION	3
METH	IODOL	.OGY	4
l.	DISA	BILITY RATE / DEMOGRAPHICS	5
II.	PERS	ONAL AND FAMILY LIFE	12
III.	CHO	CE AND CONTROL	26
	1.	Proportion of disabled women and men who live in private households	26
	2.	Proportion of disabled people living in residential institutions	28
	3.	Expenditure on social support for disabled people to live at home	30
	4.	Expenditure on residential institutional provision for disabled people	32
	5.	Enough help with personal care and household activities	32
	6. -	Home care services for disabled people	35
	7.	Number of people receiving personal or individual budgets for intependent	27
	•	living (administrative data)	37
	8.	Voting participation in general elections compared to general population	38
	9.	Active political participation	39
		10. Proportion of disabled parliamentarians	39
IV.	ACCE	SS TO GOODS AND SERVICES	41
	1.	How easy is it to use public transport	41
	2.	Household access to a private car	43
	3.	Proportion of level access public buses/trains	45
	4.	How easy to get to local shops and services	45
	5.	I ravel to work (measure to select)	4/
	6.	Key public websites meeting accessibility standards	48
	7.	Key sectoral/commercial websites meet accessibility standards	50
	8.	Regular Internet usage compared to general population	50
	9.	Percentage national language subtitles from main public TV broadcasters	51
	10.	National language subtitles from main commercial TV broadcasters	51
	11.	lext access to main emergency telephone number	52
	12.	Audio description of programmes from main public TV broadcasters	53
	13.	Audio description of programmes from main commercial IV broadcasters	53
	14.	Proportion of talking ATMs provided by main banks	54
	15.	Number of working sign language interpreters (e.g. per million population)	54
	16.	Signed programmes from main public TV broadcasters	55
	17.	Signed programmes from main commercial IV broadcasters	55
	18.	Access and use of information and communications technologies (ICT)	56
V.	EDUC	ATION AND LIFELONG LEARNING	57
	1.	Proportion of school-age disabled children attending mainstream schools	57
	2.	Disabled children of compulsory school age not enrolled in school	60
	3.	Pupils attending special schools	60
	4.	Educational attainment at school	62
	5.	Early school leavers	63
	6.	Degree / level qualification compared to general population	64
	7.	Disabled students in higher education	65
	8.	Highest level qualification	65
	9.	Participation rate in life-long learning	65
	10.	Participation in government training scheme	67
	11.	Transition from school to work (proposed)	68



VI.	WOF	RK AND EMPLOYMENT	. 69
	1.	Proportion of the public in favour of specific measures for equal opportunities employment	s in . 69
	2.	Disabled people who need / use personal assistance at work	. 70
	3.	Disabled people who need / use some equipment at work	.71
	4.	Disabled people who need / use special working arrangements at work	. 72
	5.	Employment rate of disabled women and men compared to general populati	on
	6.	Unemployment rate of disabled women and men compared to general	.74
		population	.74
	7.	Activity rate of disabled women and men compared to general population	.74
	8.	Inactivity rate of disabled women and men compared to general population.	.74
	9. 10	Full-time / part-time work	.74
	10.	working age people in work who would like to work more hours	. 75
	11.	Self-employed / employers	.76 76
	12. 12	Senior managers, company directors, professionals	70. 77
	15. 14	Disabled people living in jobless bouseholds compared to general peopletion	. / /
	14.	Long term unemployment	70
	15.	Disabled people who have over had paid work	70 . 70
	10.	Bronortion of disabled women and men who are low paid	70. 70
	17.	Labour market transitions (proposed)	70.
VII.	INC	DMES AND POVERTY	. 79 . 81
	1.	Households living in relative poverty by gender and age	. 81
	2.	Household income (with/without one or more disabled members)	. 82
	3.	Household savings / debt	. 82
	4.	Risk/rate of poverty (before/after social transfers)	. 84
	5.	Sources of household income	. 84
	6.	Satisfaction with standard of housing (accommodation meets needs?)	. 85
	7.	Disabled people living in inadequate housing	. 85
	8.	Housing tenure (e.g. public/private rented, owner occupation)	. 86
	9.	Expenditure on disability-related cash benefits	. 87
VIII.	CON	ICLUSIONS	. 90





# 05

#### INTRODUCTION

The Academic Network of European Disability experts (ANED) was established by the European Commission in 2008 to provide scientific support and advice for its disability policy Unit. In particular, the activities of the Network support the development of the EU Disability Strategy and practical implementation of the United Nations Convention on the Rights of Persons with Disabilities. One of the key activities is to contribute to the evidence base used for monitoring and evaluating progress on disability policies in European countries. Developing comparative indicators of policy implementation will be particularly important in relation to implementing the UN Convention and EU Disability Strategy.

In 2008, ANED completed preliminary review of the methods and indicators being used by other monitoring projects and networks internationally, focusing on the future demands of monitoring implementation of the UN Convention. During 2008 ANED also completed a preliminary mapping of comparative statistical datasets with the potential to be used for analysis relevant to disability. The reports from this groundwork, published on the ANED website, identified a wide range of data with potential for application to future indicators, but also significant gaps in knowledge.

In 2009 a small working group was formed to develop preliminary proposals for qualitative and quantitative indicators, drawing on consultation with the ANED Network and other relevant actors engaged in indicator development work, including Eurostat, the World Health Organisation, and the Council of Europe. The report presented here examines the group's proposals by focusing on the feasibility of providing data for selected quantitative indicators from existing data sources.

The working group noted that choice of priority indicators will require simplification and selection from a comprehensive range of possibilities offered by frameworks like the UN Convention. For the development of a priority list of indicators it proposed a simplified typology of domains (summarised as key words). The working group focused particularly on indicators where there are specific obligations within the Convention:

- 1. Disability rates / Demographics
- 2. Personal and family life (Live)
- 3. Choice and control (Choose)
- 4. Access to goods and services (Enjoy)
- 5. Education and lifelong learning (Learn)
- 6. Work and employment (Work)
- 7. Income and poverty (Earn)

In this report, we present first the methodology of our work and then a discussion of available data enabling us to construct a statistical indicator for each proposed item.

It is important to emphasise that it is not the purpose of this report to present new analysis of data to populate the proposed indicators but to report on the feasibility of doing this within the future work plan of ANED. Indicative figures for some items, from existing analysis, were presented at the ANED annual meeting in December 2009 (published on the ANED website) although these should not be regarded as definitive at this stage.





#### METHODOLOGY

This study is not an exhaustive list of available statistical sources.

In fact, we have analysed all surveys and administrative registers available at national, European and international level. However, for each item, we present the main sources enabling us to construct the chosen statistical indicators. Also, we have given a priority to European surveys as they guarantee a maximum of comparability across Member States and a sufficient geographical coverage for our purpose.

For each selected policy item, we present the main identified sources. They ought to provide the necessary information for the construction of the selected statistical indicator. Even in cases where we have at our disposal a 'good' statistical source, we present a second source in order to be able to compare with and assess the validity of the first source. On the other hand, if available surveys do not cover adequately the selected indicator, we present all identified sources containing fragments of the desired information. This ought to help us assess the potential and problems of existing sources.

In order to help the reader to identify easily the relevant question in the surveys, we present always the original question number of the survey in parenthesis.

We have used a certain number of criteria for the selection of statistical sources (surveys and registers), notably that they:

- 1. reflect the selected statistical indicators closely,
- 2. be the result of clear and unambiguous questions,
- 3. provide comparable results (harmonised methods),
- 4. be of good statistical quality (sample size, etc.),
- 5. guarantee collection at regular intervals,
- 6. cover all EU Member States if possible, and
- 7. ensure comparison of indicators over time.

It is important to note that current studies use mainly cross-sectional data following a static approach. However, we have favoured surveys which enable us to extend our analysis into a dynamic (longitudinal) approach in the future.

The European Commission has elaborated statistical indicators for different EU policies. Consequently, we tried to provide indicators which are consistent with other European indices.





# I. DISABILITY RATE / DEMOGRAPHICS

During discussion and consultation the following items were proposed:

- % women/men with a disability,
- % children with a disability,
- % working age adults with a disability,
- % older people with a disability,
- % ethnic minorities with a disability.

These indicators ought to provide overall quantitative information on a certain number of groups which are important for the UN Convention. The Preamble of the Convention notes the risk faced by persons with disabilities to be subject to multiple or aggravated forms of discrimination. Article 6 of the UN Convention stresses 'Women with disabilities' while Article 7 covers 'Children with disabilities'. The distinction between working age adults and older people is helpful for the monitoring of specific measures (e.g. work, health, etc.).

The European Statistics of Income and Living Condition (EU-SILC)<sup>1</sup> survey contains a small module on health, including 3 questions on the general health status and 4 questions on the unmet needs of health care. The questions on the general health status represent the so called Minimum European Health Module (MEHM) and are proposed to be used in any EU health survey or survey module, in order to link results among surveys. These 3 questions are: self-perceived health, chronic (longstanding) illnesses or conditions and limitation in activities due to health problems.

The data on chronic (longstanding) illnesses or conditions refer to the self-declaration by the respondents of whether they have or have not a chronic (longstanding) illness or condition. The data on limitation in activities due to health problems refer to the auto-evaluation by the respondents of the extent of which they are limited in activities people usually do because of health problems for at least the last 6 months.

The EU-SILC microdata enable us to estimate the per cent of people with functional limitations associated with disability who living in private households for the following groups (prevalence). It is important to acknowledge that the different measures considered throughout this report are dependent upon the use of different definitions of 'disability', 'disabled persons' or 'persons with disabilities'. These are discussed at length in the 2008 ANED report on mapping comparative data sources (with annexes on each survey definition):

- percent of women/men with a limitation (it covers persons aged 16+);
- percent of children/youth with a limitation (age 16-24);
- percent working age adults with a limitation (e.g. people aged 16/20-65);
- percent of older people with a limitation (e.g. people aged 65+);
- percent of people with a limitation by citizenship or country of birth.

There are different issues, which we need to discuss in order to assess these data.

<sup>&</sup>lt;sup>1</sup> From 2005 onwards the data are available for all EU25 Member States, Iceland and Norway. Bulgaria and Romania launched SILC in 2007. See also: 'DESCRIPTION OF SILC USER DATABASE VARIABLES: Cross-sectional and Longitudinal, Version 2005.1 from 01-06-07'; Eurostat <u>http://epp.eurostat.ec.europa.eu/portal/page/portal/statistics/themes</u>





#### People in institutions

The EU-SILC survey covers people living in private households. Eurostat considers that the exclusion of people living in institutions from the sample does not bias significantly overall estimators. However, this could be questioned for percentages covering people aged 65 or more.

EU-SILC data could be completed and compared with information provided by national disability surveys. A certain number of special surveys focussing on disability include institutions, in particular:

- France: The 'Disability and Health survey' ('Handicap Santé (HS')) took place in two steps. First, the 'Survey Disability – Health' ('Enquête Handicap-Santé Ménage') (2008) covered people in ordinary households and secondly the 'Survey Disability - Health Establishments' ('Handicap-Santé Institution') (2009) covered establishments. This survey updated the 'Survey on handicaps, disabilities and dependence' ('Enquête Handicap-incapacités-dépendance') (1998 & 1999) ;
- Spain: 'Survey on Disabilities, Personal Autonomy and Dependency' ('Encuesta sobre Discapacidades, Autonomía personal y situaciones de Dependencia'; 1999 & 2008). The survey includes two blocks one for private households and one for establishments (1. 'Encuesta dirigida a hogares', 2. 'Encuesta dirigida a centros');
- Ireland: 'Survey of long-stay units/nursing homes' (2000);
- Netherlands: 'Longitudinal Ageing Study Amsterdam" (LASA) (2005/2006). LASA focuses on physical, emotional, cognitive and social functioning in late life;
- Austria: 'Microcensus Survey on Disabled' (1995);
- Portugal: 'National Survey on Impairments, Disabilities and Handicaps' (1995);
- UK: 'Health Survey for England" (2000). The "Survey on disability and care' provides a good methodology but is relatively old (1985/6).

We might combine information stemming from both EU-SILC and national disability surveys in order to make an overall estimate of the number of persons with a disability.

In addition, since 2008, the OECD Health data<sup>2</sup> contains series for Long-term care resources and utilisation, and includes data on Long-term care recipients, either in institutions or at home. This database provides information on the:

- Number of long-term care recipients in institutions (other than hospitals);
- Number of long-term care recipients at home (formal/paid care only).

<sup>&</sup>lt;sup>2</sup> OECD data cover: Australia, Austria, Belgium, Canada, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Spain, Sweden, Switzerland, Turkey, United Kingdom and United States; <u>www.oecd.org/health/longtermcare</u>





These data do not include disabled people in institutions who do not receive long term care benefits. Also, OECD data cover only 19 Member States.

Furthermore, we might make use of the WHO Statistical Information System and the 'World Report on Disability and Rehabilitation' under preparation<sup>3</sup>. In fact, a World Health Assembly Resolution (May 2005), on "Disability, including prevention, management and rehabilitation", mandated WHO to produce a World report on disability and rehabilitation based on the best available scientific evidence. The World Report is expected to be launched and disseminated in December 2009. This report is more qualitative in description of national situations but there has been an attempt to include quantitative data where possible.

Finally, the Washington Group<sup>4</sup> (a group on disability statistics under the aegis of the Statistical Commission of the UN) aims to guide the development of a small set or sets of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, for the primary purpose of informing policy on equalization of opportunities. The second priority of the Washington Group is to recommend one or more extended sets of survey items to measure disability, or principles for their design, to be used as components of population surveys or as supplements to specific surveys. These extended sets of survey items are intended to be related to the general measure(s). The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) has been accepted as the basic framework for the development of the sets. This ought to facilitate comparability of the future national surveys that will use the Washington Group identification questions.

The EU could encourage Member States to collect data on people with disabilities in future censuses in a co-ordinated fashion, with a definition of disability based on the UN Convention. These censuses would give us baseline numbers on women/men/boys/girls with a disability.

#### <u>Age coverage</u>

Another problem concerning the coverage of available data relates to disabled children. The EU-SILC survey covers disabled persons aged 16 or more. Although all persons present in the household are reported, the question on disability concerns only people aged 16+.

The European Health Interview Survey (EHIS) covers people aged 15 or more but with national specificities<sup>5</sup>. We may note that the "European Social Survey" (ESS) covers people aged 15+, the European Quality of Life Survey people (EQLS) covers people aged 18+ and the International Social Survey Programme (ISSP) covers persons aged 18+.

There are a limited number of special surveys mainly focussing on disability which cover a larger age group. These include notably:

<sup>&</sup>lt;sup>5</sup> A common questionnaire was adopted in 2006 by the Eurostat Working Group on Public Health Statistics. It was used for the first round of the EHIS (2007/2009). Future waves are planned every five years. The EHIS modules can be implemented: 1) grouped in one separate national survey, or 2) included in existing national surveys (i.e. national HIS, LFS, other survey). In the 2004 HIS round, there was no age restriction in several countries. Certain countries have published EHIS results (e.g. Malta) but most published data refer to the HIS 2004 data collection round, which covers for most countries the period 1999-2003. These data cover EU-27 (excluding Luxembourg), Iceland, Norway, Switzerland.





<sup>&</sup>lt;sup>3</sup> <u>http://www.who.int/disabilities/publications/dar\_world\_report\_concept\_note.pdf</u>

<sup>&</sup>lt;sup>4</sup> <u>http://unstats.un.org/unsd/methods/citygroup/washington.htm</u>

Austria:	The 'Microcensus Survey on Disabled' covers all ages;
Spain:	The survey on 'Disabilities, Personal Autonomy and Dependency' covers all
-	persons living in private households and persons aged 6+ in institutions;
France:	The 'Health & Disability' ('Handicap Santé' - HS) covers all ages;
NL:	The 'Permanent Quality of Life Survey' (POLS) covers people aged 12+;
Poland:	The 'Health Care in Households' (HCH) covers all ages;
UK:	The 'General Household Survey' (GHS) covers all ages.

In addition, the OECD undertook a study in 2005-06 to assess disability trends among elderly people and the implications for the future number of elderly people who might need long-term care<sup>6</sup>. The study focuses on the prevalence of severe disability among people aged 65 and over in a dozen OECD countries (Australia, Belgium, Canada, Denmark, Finland, France, Italy, Japan, the Netherlands, Sweden, the United Kingdom and the United States).

The estimation of the number of disabled children poses special problems. For this reason, the questions on disability are different for children and adults. This explains partly the exclusion of children from most surveys.

Now we have two methods in order to estimate prevalence of disability among children. First, previous disability surveys may provide an estimation for the number of disabled children aged 6 to 15 years. Secondly, the EU-SILC survey provides enough information in order to make extrapolations for younger ages. In fact, available EU-SILC microdata indicate that there is a stable relation between age and prevalence of disability in all Member States. Often it is represented by a logistic function. This age related prevalence is determined by a specific rate of progression and a specific level effect for each Member State.

This information would enable us to present an estimation of disability prevalence for persons aged 6 years or more and notably for the age group 6 to 15 years. This includes all children, to disaggregate those with impairment from birth it would be necessary to consider medical surveys (but in general their estimations are close to the extrapolations it is possible to do with existing data based on age group of zero years).

# Definitions of disability

The general question on <u>limitations in activities people usually do</u> can be found in most surveys. However, some distinguish 'Limited – Not limited' while others 'Strongly limited – Moderately/to some extent limited – No limited'. This might affect the overall estimate of the prevalence of disability.

A more interesting aspect concerns the reference activities. A limited number of surveys report '<u>work limitations'</u>. The standard question with some variations is: "Do you have any health problems or disabilities which limit the amount or type of work you can do"? We may cite the following surveys:

<sup>&</sup>lt;sup>6</sup> See, for example, Projecting OECD health and long-term care expenditures: what are the main drivers? Economics Department working papers, 477; Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability? By Jens Lundsgaard; Health Working Papers 20, OECD, 2005; Society at a Glance 2009: OECD Social Indicators





- 1. the LFS Ad hoc module 2002 and the expected LFS 2011 ad hoc module on employment of disabled people<sup>7</sup>;
- 2. the' European Disability Social Integration Module' (EDSIM)<sup>8</sup> (2009);
- 3. the 'Health Disability and Work' ('Santé, Handicap et Travail') survey in France (2007);
- 4. the 'British Household Panel Survey' (2007).

It might be interesting to provide two different definitions of disability for people of working age and estimate first people with limitations in everyday life and secondly people with work limitations. These two estimates provide complementary information. Similarly, for children, it might be interesting to estimate both children with limitations in everyday activities and children with special education needs.

Little attention has been paid to <u>administrative definitions</u> of disability included in some surveys, but these enable us to establish a bridge between traditional surveys (based on self-declared limitations) and administrative registers (based on recognised disabilities). Administrative definitions of disability have been introduced in current surveys through two methods. The direct method ask people if they have a recognised disability by the relevant authorities while the indirect method reports if they receive any disability related benefit.

The following surveys enable us to measure the number of people with a recognised disability:

- 1. The EU-SILC (annual);
- 2. The French 'Health, Disability and Work' ('Santé, Handicap et Travail') (2007);
- 3. The Spanish 'Disabilities, Personal Autonomy and Dependency' (2008);
- 4. The Polish 'Health Care in Households' (2003);
- 5. The British 'Household Panel Survey' (2007).

The EU-SILC survey reports whether the interviewed persons receive a disability related benefit. Consequently, we can measure the percent of people who receive a disability related benefit and compare this with the percent of people who report a limitation. The number includes different disability benefits including 'Disability benefits to disabled children in their own right, irrespective of dependency'<sup>9</sup>.

During the 1980s and 1990s most national disability surveys focussed on the estimation of the number of disabled people. Subsequent surveys focussed on the impact of disability and recognised that each definition (limitation in daily activities, work restrictions and administrative definitions) had each their advantages and disadvantages in terms of social participation, work integration, etc. depending on the goal pursued.

The issue of multiple definitions is not specific to disability; the same surveys sometimes use several definitions for e.g. unemployment. It is in fact desirable to use different definitions depending on the policy goal pursued (e.g. social participation, work, social security, etc.).

<sup>&</sup>lt;sup>9</sup> See "Description Of SILC User Database Variables: Cross-sectional and Longitudinal, Version 2005.1 from 01-06-07", Directorate E: Social and regional statistics and geographical information system Unit E-2: Living conditions, Eurostat, p221.



<sup>&</sup>lt;sup>7</sup> 'TF proposal for the 2009 LAMAS meeting'; Eurostat

<sup>&</sup>lt;sup>8</sup> The EDSIM module was tested in 2009 by 10 countries under EUROSTAT grant. It had been tested previously in the UK, Italy and Lithuania.

For example, surveys focusing on work issues might examine work restrictions (combined with assistance needed and received) in terms of amount of work, kind of work and mobility to and from work. This approach helps us to take into account contextual factors and related assistive technologies which are important for the elaboration of relevant policies.

The Minimum European Health Module (MEHM) could be included in a wide range of surveys in parallel with specific disability definitions (e.g. work restrictions) depending on what we want to monitor or assess.

In fact, we need a common base for comparison across different surveys; otherwise we risk having a multitude of specific surveys with their related definitions (work restrictions for labour policies, special education needs for educational policies, mobility limitations for transport policies, etc.).

The introduction of Minimum European Health Module (MEHM) would favour comparability of results across national surveys and thematic surveys (employment, education, social relations, etc.). But this does not necessarily take into account the ICF approach on the interaction between disability and society. It is unclear when it will be used...

The <u>UN Convention on the Rights of Persons with Disabilities</u> provides that (Article 1) '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'. While all recent surveys take into account the different types of disability (physical, mental, etc.) few of them incorporate the 'interaction' with social and environmental barriers.

The European Disability and Social Integration Module (EDSIM) is a good example of such an approach. It aims at identifying individual barriers (health conditions, impairments) as well as environmental factors (convenience, lack of assistive devices or personal help, etc.). Also, it highlights different dimensions such as what a person can do, what he would like to do and what are the main reasons preventing him from achieving his aspirations.

Also, the LFS ad hoc module on employment of disabled people asks first on limitations in working activities and then aims at identifying 'Main reason for limitation in work ... that is not related to longstanding health conditions/diseases or basic activity difficulties'. These main reasons include 'Lack or poor transportation to and from workplace', etc.

This approach could be generalised in thematic surveys. We use the term 'thematic' surveys, because the questionnaire ought to include a question on contextual factors and these factors depend on the theme of each survey. For example, these factors (barriers) are different for mobility surveys (e.g. accessible transport) compared to labour surveys (e.g. technical aids).

#### Dynamic aspects

There is a lot of information concerning the dynamic aspects of disability which is not exploited. A health condition or a disability status is not a static situation. For example, we do not know how many people declaring a limitation in the first year declare to be in the same or in a different state in the next year. Recent studies indicate that the worsening/deterioration of health status is an important behavioural determinant.





Also, information on transitions between different health and disability situations might be valuable to assess the impact of certain general policies. Several longitudinal surveys contain information on transitions between states of disability, notably the EU-SILC.

Consequently, it might be useful to present the number of transitions between different states:

Disability status in previous	Disability status in next year	%
year		AT BE DK DE EL FR
		etc
	Limited	X%
Limited	Not limited	Υ%
	Total	100 100 100 100 100
		100
	Limited	X%
Not limited	Not limited	Υ%
	Total	100 100 100 100 100
		100

# Table 1: Transitions by disability status (Transition probability matrix)

These are one step transition frequencies (from one year to the next) but longer transition periods could be envisaged.

The same table can be provided for specific groups (e.g. gender, age groups and education).

#### <u>Summary</u>

We could combine information stemming from both EU-SILC and national disability surveys in order to make an overall estimate of disability prevalence (by age, gender and origin/nationality) by Member State. Also, we might valorise the current WHO and Washington group initiatives.

National disability surveys (for certain Member States) enable us to estimate the prevalence of disability among children (6 to 15 years). This experience should be used to extend certain surveys to cover a broader age range.

In the short term, the Minimum European Health Module (MEHM) could be inserted in different national and European thematic surveys. This could provide a common reference base for comparison of disability prevalence across Member States as well as across thematic surveys.

In the medium term, we might retain different definitions of disability according to the goal pursued by the survey and incorporate questions on the interaction between disability and social/physical environment. The UN Convention could be the reference framework.

Finally, we ought to valorise the longitudinal dimension of current surveys in order to analyse dynamic aspects.

A certain number of comparisons can be found in *Study of compilation of disability statistical data from the administrative registers of the member states study financed by dg employment, social affairs and equal opportunities* (CONTRACT NO VC/2006/0229 – EUR 363,268.42)APPLICA & CESEP & EUROPEAN Centre Final Report November 2007; notably Chapter I.





# II. PERSONAL AND FAMILY LIFE

Article 23 of the UN Convention (Respect for home and the family) is important here, but also relevant elements of other Articles for example Article 10 (Right to life), Article 16 (Freedom from exploitation, violence and abuse), etc.

During discussion and consultation a certain number of indicators were proposed. They focus on people with disabilities and cover the following items (with possible priority indicators shown in italics):

- 1. Public think that being disabled tends to be a disadvantage in society
- 2. Public think that disability discrimination is widespread in society
- 3. Public think that disability discrimination is more common now than it was
- 4. Subjective well-being/happiness of disabled women and men compared to general population
- 5. Time Use by Activity (work life balance?)
- 6. Free Time Spent by Activity
- 7. Victims of violence/crime
- 8. Disabled women and men living alone compared to general population
- 9. Disabled people living as a couple
- 10. Disabled people ever married
- 11. Social contacts and friendships
- 12. Public have friends or acquaintances who are disabled
- 13. Disabled women and men who are parents compared to general population
- 14. Women's fertility rates compared to general population
- 15. Age at first child birth

# 1. Public think that being disabled tends to be a disadvantage in society

The Eurobarometer (EB)<sup>10</sup> 2006 examined the extent to which EU citizens interact with various different groups in the population and provides a general overview at the EU level of people's perception of discrimination in their country, their assessment of the position of disadvantaged people in society and their attitudes about discrimination and inequality.

The survey also measures whether people believe that belonging to a particular group tends to be an advantage or a disadvantage in their country's society. A question asks (QA6): "Would you say that the fact of belonging to the following groups tends to be an advantage or a disadvantage, or neither, in (nationality) society at the current time? The fact of...

- 1. Being disabled
- 2. Being a Roma
- 3. Being aged over
- 4. Being a person of a different ethnic origin than the rest of the population
- 5. Being homosexual
- 6. Being part of a religion that is different from the main

http://ec.europa.eu/employment\_social/eyeq/uploaded\_files/documents/eurobarometer\_report\_en.pdf





<sup>&</sup>lt;sup>10</sup> Eurobarometer is a series of surveys regularly performed on behalf of the European Commission. The survey was carried out in June and July 2006 in the 25 EU Member States and in Romania and Bulgaria.

- 7. Religion in the country
- 8. Being a woman
- 9. Being aged under
- 10. Being a man".

The European Values Survey (EVS)<sup>11</sup> includes the main domains of life: work and leisure time, family and sexuality, religion, politics and ethics. The EVS contains a question which is complementary to the one included in the Eurobarometer. The question (Q84) is: "To what extent do you feel concerned about the living conditions of:

- 1. Elderly people
- 2. Unemployed people
- 3. Immigrants
- 4. Sick and disabled people
- 5. Children in poor families".

The Eurobarometer survey gives the percentage of people who think that being disabled tends to be a disadvantage in society.

# 2. Public think that disability discrimination is widespread in society

The Eurobarometer 2006 survey asked (QA1): "For each of the following types of discrimination, could you please tell me whether, in your opinion, it is very widespread, fairly widespread, fairly rare or very rare in (our country)?

- 1. ethnic origin
- 2. disability
- 3. sexual orientation
- 4. age
- 5. religion or beliefs
- 6. gender".

The Eurobarometer survey gives the percentage of people who think that disability discrimination is widespread in society.

# 3. Public think that disability discrimination is more common now than it was

The Eurobarometer 2006 survey asked (QA2): "If you compare the situation with 5 years ago, would you say that the following types of discrimination are more common or less common in (our country)? Discrimination on the basis of....

<sup>11</sup> The last round (2005/08) included in particular the following countries: BG, CY, FI, FR, DE, UK, IT, NL, PL, RO, SL, SP, SW, CH and TR. European Values Study Foundation: http://www.gesis.org/en/services/data/survey-data/european-values-study/





- 1. ethnic origin
- 2. religion or beliefs
- 3. age
- 4. sexual orientation
- 5. disability
- 6. gender".

The Eurobarometer survey gives the percentage of people who think that disability discrimination is more common now than it was 5 years ago.

# 4. Subjective well-being / happiness of disabled women and men compared to general population

The European Social Survey (the ESS)<sup>12</sup> is a biennial multi-country survey covering over 30 nations. The ESS survey asks: "Taking all things together, how happy would you say you are? Please note: Extremely unhappy: 0 ... Extremely happy: 10".

Also, this survey asks: "Are you hampered in your daily activities in any way by any longstanding illness, or disability, infirmity or mental health problem? (A lot, To some extent, No).

However, the sample is relatively small and this might generate statistical problems when we take into account additional criteria (age, gender, etc.).

Consequently, we may construct an indicator presenting subjective well-being / Happiness for people with and without disabilities by sex. Again in this example, the common use of a disability definition based on illness/disability is indicated. The 'Long standing illness' component excludes temporary health problems and would generally be regarded as inclusive within the UN definition of disability. However, we have to be cautious in interpreting the results.

The European Quality of Life Survey (EQLS) is run by the European Foundation for the Improvement of Living and Working Conditions<sup>13</sup>. The EQLS puts a similar question: "All things considered, how satisfied would you say you are with your life these days? Please tell me on a scale of 1 to 10, where 1 means very dissatisfied and 10 means very satisfied" (Q29). Also, the EQLS asks about "Chronic (long-standing) physical or mental health problem, illness or disability" and whether this hampered their daily activities.

Again, we may construct an indicator presenting subjective well-being / Happiness for people with and without disabilities by sex. Again the sample is relatively small.

These questions are very general. It is thus interesting to identify the area which contributes most in the sentiment of happiness/unhappiness and satisfaction/dissatisfaction.

<sup>&</sup>lt;sup>13</sup> <u>http://www.eurofound.europa.eu/areas/qualityoflife/eqls/2007/index.htm</u>. It covers: EU 27, NO, TR, FYROM and HR.



<sup>&</sup>lt;sup>12</sup> <u>http://www.europeansocialsurvey.org/index</u>. It covers: AT, BE, BG, HR, CY, CZ, DK, EE, FI, FR, DE, EL,

HU, IE, IS, LV, LT, NL, NO, PL, PT, RO, SK, SL, ES, SE, UK, CH, TR, RU, UKR. Last survey: 2008.

In this direction, the EQLS asks "Could you please tell me on a scale of 1 to 10 how satisfied you are with each of the following items, where 1 means you are very dissatisfied and 10 means you are very satisfied? (Q40): 1. Your education, 2. Your present job, 3. Your present standard of living, 4. Your accommodation, 5. Your family life, 6. Your health, 7. Your social life".

Other cross-tabulations could be done with the economic status (notably work, unemployment, inactivity). However, both the ESS survey and the EQLS survey use a relatively small sample. Consequently, these surveys might deliver indicators which are not statistically powerful.

It is worth noting that the International Social Survey Programme (ISSP) has included a new module, 'Leisure Time & Sports', run for the first time in 2007<sup>14</sup>. The source questionnaire includes a question on Happiness and Satisfaction. However, the health bloc of questions does not include disability.

We may construct an indicator presenting subjective well-being / Happiness for people with and without disabilities by sex. The area of satisfaction/dissatisfaction completes the former indicator.

# 5. Time use by activity (work life balance)

The Harmonised European Time Use Surveys<sup>15</sup> (HETUS) is run every five years. The Time use data are collected by means of time diaries. Respondents record their activities in time diaries, using their own words. The diary covers 24 hours. With some exceptions each respondent fill in diaries for two diary days. It contains a household and an individual questionnaire. Apart from the usual socio-demographic variables, the survey includes the following categories of activities: personal care, employment, study, domestic work, leisure and travel.

Also, the HETUS survey guidelines (2008) include a question on disability (132): "Are you hampered in your daily activities by this physical or mental health problem, chronic illness or disability"? Again, the disability/illness identifier is employed. This has some conceptual limitations but is often used to present statistics on the population of 'disabled' people.

http://w3.unece.org/pxweb/dialog/varval.asp?ma=0105\_GELB\_TimeUseStructur\_r&ti=Time+Use++by +Activity%2C+Sex%2C+Country+and+Year&path=%2E%2E%2FDATABASE%2FStat%2F30%2DGE%2F 98%2DGE%5FLifeBalance%2F&xu=&yp=&lang=1\_





<sup>&</sup>lt;sup>14</sup> It covers 30 countries. The European countries are: AT, BG, CY, CZ, DK, FI, BE (Flanders), FR, DE, UK (GB), HU, IE, IT, LV, NL, Northern Ireland, NO, PL, PT, SL, ES, SE, CH.

<sup>&</sup>lt;sup>15</sup> The Time Use Surveys cover: Belgium, Denmark, Germany, Estonia, Spain, France, Italy, Latvia, Lithuania, Hungary, Netherlands, Poland, Slovenia, Finland, Romania, Sweden, UK and Norway. Most countries cover people in private households aged 10+. In this case, the survey contains a child and an adult questionnaire.

http://circa.europa.eu/Public/irc/dsis/tus/library?l=/comparable\_statistics/comparable\_statistics/\_EN\_ 1.0\_&a=d

The United Nations Economic Commission for Europe (UNECE) presents aggregated data for Austria, Belgium, Canada, Estonia, Finland, France, Germany, Hungary, Italy, Kazakhstan, Kyrgyzstan, Latvia, Lithuania, Netherlands, Norway, Poland, Portugal, Spain, Sweden, Switzerland, FYROM, Turkey, UK, United States. The most recent data cover 2006.

The UN Convention protects the following group: 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.' Survey identifier questions usually include a measure of time duration for the condition (e.g. on e year) and some terminology that implies the concept of being 'hindered' (or 'hampered') in an everyday environment. These issues were discussed at some length in the ANED synthesis report from 2008 (by Wim van Oorschot)<sup>16</sup>.

Some countries e.g. France and the UK included a health/disability module in 1998/2000 and Spain in 2002/2003. Also, some Member States (e.g. UK) added in latter surveys "1) Do you have any health problems or disabilities that you expect will last for more than one year? Are you hampered in your daily activities by this physical or mental health problem, chronic illness or disability? Severely / To some extent"?

Consequently, we may estimate the structure of a representative day for a person with and without a disability. This can be done separately for children and adults in most participating countries.

We can approach the relationship between working and non-working life through the EU guideline 'promote a lifecycle approach to work through [among others] better reconciliation of work and private life'.

In Eurofound surveys, two different sets of questions address the issue of work–life balance. In the European Working Conditions Survey (EWCS)<sup>17</sup>, the work–life balance question asks respondents if working hours fit in with family or social commitments outside work. However, this survey does not identify people with disabilities. The only relevant questions concerns work status: people unable to work due to long-term illness or disability. This is a very restrictive definition of disability.

The EQLS approaches work–life balance from a slightly different angle, through a threefold question concerning the following elements (Question 11): "How often has each of the following happened to you during the last year?

- 1. I have come home from work too tired to do some of the household jobs which need to be done;
- 2. It has been difficult for me to fulfil my family responsibilities because of the amount of time I spend on the job;
- 3. I have found it difficult to concentrate at work because of my family responsibilities".

The EQLS survey includes a question on activity limitations. Consequently, we can assess the work-life balance for people with and without disabilities.

In the above, gender is an important dimension. In fact, domestic work and care provision is not divided equally between women and men. Consequently, it is interesting to present these indicators by gender. This might reveal a double disadvantage for disabled women, as disabled and as women.

<sup>&</sup>lt;sup>17</sup> http://www.eurofound.europa.eu/surveys/index.htm





<sup>&</sup>lt;sup>16</sup> See also, <u>http://www.officefordisability.gov.uk/research/definitions.php</u>

We can estimate the structure of a representative day for a person with and without a disability. This can be done separately for children and for adults in certain participating countries.

It would be interesting to present these estimators by gender.

From a different perspective the EQLS survey enables us to estimate if people with and without disabilities are satisfied with their work-life balance.

# 6. Free time spent by activity

The HETUS survey distinguishes the following activities in the diaries:

- 1. VOLUNTARY WORK AND MEETINGS
  - a. Organisational work
  - b. Informal help to other households
  - c. Participatory activities
- 2. SOCIAL LIFE AND ENTERTAINMENT
  - a. Social life
  - b. Entertainment and culture
  - c. Resting, time out
- 3. SPORTS AND OUTDOOR ACTIVITIES
  - a. Physical exercise
  - b. Productive exercise
  - c. Sports related activities
  - HOBBIES AND COMPUTING
    - a. Arts and hobbies
    - b. Computing
    - c. Games
  - MASS MEDIA

4.

5.

- a. Reading
- b. TV, Video and DVD
- c. Radio and recordings

Each category can be detailed further. Also, the survey reports information on time spent for travel by purpose:

- 1. Travel to/from work
- 2. Travel related to study
- 3. Travel related to shopping and services
- 4. Travel related to childcare
- 5. Travel related to other household care
- 6. Travel related to voluntary work and meetings
- 7. Travel related to social life
- 8. Travel related to other leisure
- 9. Travel related to changing locality
- 10. Other or unspecified travel purpose

Indicators on mobility are presented below.





It is therefore possible to estimate the time spent for each leisure activity by people with and without disabilities. As before, it would be interesting to present this estimate separately for women and men.

The HETUS survey enables us to estimate the time spent for each activity by people with and without disabilities.

Copies of disability-specific questions and links to surveys were included in the annex to the 2008 ANED synthesis report.

# 7. Victims of violence and crime

The EHIS asks the following question "Thinking about the past 12 months, to what extent were you exposed to crime, violence or vandalism at home or in the area where you live"? (EN.2)

This information enables us to estimate the percent of people with and without disability exposed to crime, violence or vandalism.

Age and gender are important dimension as gender and age differences appear to be significant. This indicator ought to be computed by gender and by age group.

Concerning other surveys, we may note the ESS questions:

- 1. Have you or a member of your household been the victim of a burglary or assault in the last 5 years"? (QC5; Yes, No).
- 2. How safe do you or would you feel walking alone in this area after dark? (QC6; very safe, safe, unsafe or, very unsafe).
- 3. How often, if at all, do you worry about becoming a victim of violent crime? Please choose your answer from this card.(QC9; All or most of the time, Some of the time, Just occasionally, Never).

The above survey has some weaknesses. The first question covers not only the person interviewed but also 'a member of your household'. The second question stresses geographical (local) aspects. Finally, the last question is subjective. However, we can consider using it as an overall indicator, and it could be linked with the next question which measures the impact on people's life: 'Does this worry about becoming a victim of violent crime have a... serious effect on the quality of your life, some effect, or no real effect on the quality of your life?' (Q C10)

The EU-SILC aims to assess whether the respondent feels 'crime, violence or vandalism in the area' to be a problem for the household. There is no common standard of what is a problem. Area refers to the place situated close to the place of residence (where you usually shop, walk, the way home). This enable us to assess whether for a given area, there is a difference between households comprising people with and without limitations. But this might be misleading as violence can take place inside the household. The EQLS asks a similar question.

A review of surveys on crime and violence reveals that there are two main types of survey.





The first set of surveys is based on the EU International Crime Survey (EU-ICS)<sup>18</sup> and the European Victimisation Survey <sup>19</sup>. The International Crime Victim Survey (ICVS) is a programme of standardised sample surveys to look at householders' experience with crime, crime prevention and feelings of unsafety in a large number of countries. Also, Eurostat initiated in 2006 the development of a European victimisation survey instrument, to be used for collecting comparable crime victimisation data from all EU countries.

The Eurostat victimisation survey will be piloted in Finland in 2009. Both European surveys report personal characteristics but do not include disability. The only reference is on economic status (work, unemployed, retired/disabled, etc.) and consequently very restricted. It might be interesting to encourage the inclusion of the Minimum European Health Module (MEHM) with its question on activity limitations.

The second set of surveys focuses on violence in an ageing society. According to WHO, abuse of the elderly is a problem that may continue to grow because many countries experience a rapidly ageing population. The abuse of elderly includes physical, sexual and psychological abuse as well as neglect. Elderly people are especially vulnerable to economic abuse, in which relatives or caregivers make improper use of their funds and resources (WHO, 2000). Information on the frequency of elder abuse has relied mainly on surveys conducted in a limited number of countries. The UK 'Study of Abuse and Neglect of Older People' (2005)<sup>20</sup> covers people aged 66+ and presents 'Limiting long-term illness' and adopts a classification of long-term illness close to ICIDH. The type of mistreatment included: Neglect, Financial, Psychological, Physical and Sexual. The results reveal that the level of mistreatment was higher for people with: a self-reported health status of bad or very bad, a limiting long-term illness, a lower quality of life, and for those suffering from depression. The UK survey might be a model for future surveys.

The French surveys<sup>21</sup> have a limited scope as they cover declared registered mistreatment complaints. Similar surveys on abuse and mistreatment of elderly people in the Netherlands (1994) and Finland (1992 and 2005) do not include questions on disability. The French FEHAP 2007 includes institutions. The second 'Abus et négligence chez les personnes âgées tel que perçu par les intervenants dans des services à domicile' (2001) clearly excludes them.

EHIS information enables us to estimate the percent of people with and without disability exposed to crime, violence or vandalism. This percent can be computed by sex and age. Age and gender are important variables and ought to be presented. As noted above : A common questionnaire was adopted in 2006 by the Eurostat Working Group on Public Health Statistics. It was used for the first round of the EHIS (2007/2009). Future waves are planned every five years.

<sup>19</sup>The draft survey instrument was finalised in 2007, and is currently being tested in 18 member countries. The development work is anticipated to be completed in 2010. Eurostat.

<sup>20</sup> It covers people living in private households (including sheltered accommodation).

<sup>21</sup> Enquête bientraitance / maltraitance FEHAP (2007) and 'Abus et négligence chez les personnes âgées tel que perçu par les intervenants dans des services à domicile' (2001).





<sup>&</sup>lt;sup>18</sup> The International Crime Victim Survey (ICVS) is a programme of standardised sample surveys to look at householders' experience with crime, policing, crime prevention and feelings of unsafety in a large number of countries. The EU-ICS uses the International Crime Victim Survey – ICVS methodology. EU-ICS: The current dataset covers 18 countries of the European Union, notably, EU-15 plus Estonia, Poland and Hungary. New countries with comparative measurements include the United States, Bulgaria, Croatia, and Turkey. <u>http://rechten.uvt.nl/icvs/</u>

Also, we can estimate whether this worry about becoming a victim of violent crime has a... serious effect on the quality of life by disability status, sex and age.

Concerning future surveys, efforts ought to be deployed to insert the MEHM into victimisation surveys and to harmonise surveys on ageing.

# 8. Disabled women and men living alone compared to general population

The EU-SILC survey presents information on the composition of households. For each member of the household we have age, sex and relation with other members (mother, father). This enables us to distinguish between people living alone or in a household. As noted above, the EU-SILC survey presents also limitation in activities people usually do because of health problems (1. yes, strongly limited, 2. yes, limited, 3. no, not limited). Again, this refers to 'limitation in activities'. On page 5 we describe the EU-SILC questions.

Consequently, we may estimate the percentage of disabled men and women living alone compared to general population.

Several other surveys enable us to estimate this indicator, in particular the EQLS and EHIS surveys.

Available data are sufficient in order to estimate the percent of persons with and without disabilities living alone.

#### 9. Living as a couple

This indicator completes the previous one.

The EU-SILC presents information on the type of "Consensual Union" for partners living in the same household with the following possible responses:

- 1. yes, on a legal basis
- 2. yes, without a legal basis
- 3. no

Generally, all available surveys present information on the composition of the household. For example, the EHIS survey presents similar information. First, it asks: "What is your legal marital status"? (HH.5):

- 1. single, that is, never married
- 2. married (including registered partnership)
- 3. widowed and not remarried
- 4. or divorced and not remarried (including legally
- 5. separated and dissolved registered partnership)?

Latter, it specifies: "May I just check, are you living with someone in this household as a couple"? (HH.6). The answer is Yes, on a legal basis or Yes, without a legal basis.





Several other surveys enable us to estimate this indicator, notably the EQLS survey.

Available data are sufficient to enable us to estimate the percent of persons with and without disability living as a couple.

We can present this indicator by sex.

#### 10. Married ever/married

The EU-SILC presents 'Marital status' (PB190) and distinguishes:

- 1. Never married
- 2. Married
- 3. Separated
- 4. Widowed
- 5. Divorced

Marital status is the conjugal status of each individual in relation to the marriage laws of the country (i.e. de jure status). It therefore does not necessarily correspond with the actual situation of the household in terms of co-habitation, living arrangements, etc.

Furthermore, as noted above, the EU-SILC survey presents limitation in activities people usually do because of health problems (1. yes, strongly limited, 2. yes, limited, 3. no, not limited).

Consequently, we may estimate the percentage of people with and without disabilities who have been ever married. Similar information is provided by the big majority of surveys (EQLS, EHIS, etc.).

Available data are sufficient to enable us to present the percentage of people with and without disability married, ever-married.

We can estimate this indicator by sex and age.

# 11. Social contacts and friendships

There are several surveys presenting social contacts and friendships. However, both the definition for disability and classifications used for contacts and activities differ sharply across surveys.

The European Social Survey (the ESS)<sup>22</sup> is a biennial multi-country survey covering over 30 nations (fully annotated and desctribed in the annex to the 2008 ANED report).

<sup>&</sup>lt;sup>22</sup> <u>http://www.europeansocialsurvey.org/index</u>. It covers: AT, BE, BG, HR, CY, CZ, DK, EE, FI, FR, DE, EL, HU, IE, IS, LV, LT, NL, NO, PL, PT, RO, SK, SL, ES, SE, UK, CH, TR, RU, UKR. Last survey: 2008.



It asks: "Are you hampered in your daily activities in any way by any longstanding illness, or disability, infirmity or mental health problem? Also, the question bloc on personal life includes the following questions:

- "How often do you meet socially with friends, relatives or work colleagues (Never, Less than once a month, Once a month, Several times a month, Once a week, Several times a week, Every day)".
- "Do you have anyone with whom you can discuss intimate and personal matters"? (Yes, No).

Isolation is an important consideration. It would therefore be interesting to combine this information with the following questions:

- Are you currently living with your husband/wife? (Yes, No), and
- Are you currently living with a partner? (Yes, No).

However, the sample is relatively small and this might generate statistical problems if we take into account additional criteria (gender, periodicity of contacts, etc.).

The EDSIM includes a question concerning 'Meeting other people with similar hobbies or interests'. The possible answers being: (data not yet available)<sup>23</sup>.

- 1. I do this activity as much as I want to
- 2. I do this activity but would like to do it more often
- 3. I don't do this activity but would like to do it
- 4. I don't do this activity and do not want to

Other questions in the EDSIM cover:

- 6. Visiting family members,
- 7. Visiting friends,
- 8. Attending family functions and gatherings,
- 9. Attending social events with friends.

Furthermore, it asks:

- What is stopping you from doing (more of) these activities? (Different options for answer);
- Overall, how much choice do you have over how you spend your free time...

The European Quality of Life Survey (EQLS) includes a question concerning:

- "On average, thinking of people living outside your household how often do you have direct (face-to-face) contact with...(Q32)?
- "On average, how often do you have contact with friends or family living outside your household by phone, email or by post?

<sup>&</sup>lt;sup>23</sup> We should note that EDSIM is in pilot and possible modification, so that items may change compare to those available to the rapporteur at the time of this report in 2009





This is an important distinction since mobility limitations may restrict geographical movement but may be compensated by new means of contacting people.

The answer in each case distinguishes two dimensions:

- 1. the family link (a. Any of your children, b. Your mother or father, c. Any brother, sister or other relative, d. Any of your friends or neighbours), and
- 2. the frequency (More than once a day, Every day or almost every day, At least once a week, Once or twice a month, several times a year, less often)

The EQLS asks about "Chronic (long-standing) physical or mental health problem, illness or disability" and whether this hampered their daily activities.

Also, it presents marital status. The EQLS takes the most detailed approach. However, it is not a regular survey. The first took place in 2003 and the second in 2007/2008. Also, the EQLS covers people aged 18 or more while the ESS covers people 15 or more (again, this survey is annotated in the 2008 ANED report)

Finally, it is interesting to note SHARE<sup>24</sup> (Survey of Health, Ageing and Retirement). The survey is held among people aged 50 or older. A question treats the consequences of illness and disability on social contacts. The question is "What long-term effects, if any, has injury, ill health or disability had on your life"? Answers include: 'Made my social life more difficult' (1.Limited my opportunities for paid work, 2.Had a negative effect on my family life, 3.Had a positive effect on my family life, 4.Made my social life more difficult, 5.Limited my leisure activities, 6.Made me determined to get the best out of life, 7.Opened up new opportunities, 96.None of these, 97.Other).

Available data are sufficient for the estimation of the frequency of social contacts by sex, age and marital status by people with and without disabilities.

The EDSIM module will enable us to assess the percent of people who face barriers (lack of assistance) or limited choices in their contacts (see footnote 23)

# 12. Public have friends or acquaintances who are disabled

The Eurobarometer 2006 survey asked (QD47): "Do you have friend or acquaintances who are...?

- 1. of a different religion or have different beliefs than you
- 2. disabled
- 3. of a different ethnic origin than you
- 4. homosexual
- 5. "Roma"

<sup>&</sup>lt;sup>24</sup> <u>http://www.share-project.org/</u>. Countries of the 2008/2009 wave include: Austria, Belgium, Czech Republic, Denmark, France, Germany, Greece, Italy, The Netherlands, Poland, Slovenia, Spain, Sweden, Switzerland





The Eurobarometer survey gives the percentage of people who have friends or acquaintances who are disabled, although questions may vary from year to year. The items we consider would be most useful are included in the ANED IDEE draft proposals.

# 13. Proportion of disabled people who are parents

The European Quality of Life Survey (EQLS) is run by the European Foundation for the Improvement of Living and Working Conditions. It includes a question on "How many children of your own do you have"? (Q31). On the other hand, it asks about "Chronic (long-standing) physical or mental health problem, illness or disability" and whether this hampered their daily activities. Also, it presents the marital status. However, the sample is small (35000) and the standard errors very high. Also, it is not an annual survey. The first took place in 2003 and the second in 2007/2008.

The European Health Interview survey (EHIS) records all persons living in the household. Also, the survey asks (HS.3) "For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?". This information enables us to identify and to estimate people with disabilities who are parents. However, if the child is not living in the same household, it is not reported.

The EU-SILC presents limitation in activities because of health problems. The EU-SILC also reports the 'Personal ID (RB230) of mother' and the 'Personal ID (RB220) of father' for 'all current household members (of any age) and former household members'. This information enables us to estimate the proportion of disabled people who are parents.

We can estimate the proportion of people with and without disabilities who are parents. We can present this indicator by sex and degree of limitation. Each option has its advantages and disadvantages (EU SILC is the most complex to do)..

# 14. Disabled women's fertility rate compared to general population

The EU-SILC reports for 'all current household members (of any age) and former household members' the 'Membership status'. For current household members it distinguishes between: 1. Moved into this household from another sample household since previous wave, 2. Move into this household from outside sample since previous wave, 3. Newly born into this household since last wave, etc. This information coupled with the birth date enables us to distinguish new births. On the other hand, for all current household members (of any age) the EU-SILC reports information on mother (Personal Id (RB230) of mother).

As noted above, the EU-SILC survey presents limitation in activities people usually do because of health problems. Consequently, by combining these elements, we can present the fertility rate for the year in question. However, problems might arise if the child does not live in the household.

The EQLS presents all persons living in the same household, their birth rate and their relation to adults.





The EU-SILC survey enables us to construct a proxy indicator presenting the number of new births by disability status of the mother.

# 15. Age at first child birth

Several surveys (the EU-SILC, EHIS, and EQLS) enable us to make the link between a person and his mother. Since we have the disability status of a woman, we can estimate the age at first child birth. However, we have to note that these studies focus on all persons living in the same household.

Also, we have to add two additional remarks which constitute important restrictions; First, household members (old and new) cover persons alive. Deceased children are not counted. Secondly, a woman may become disabled several years after the child birth.

Consequently, the age at first child birth is not unambiguous information. For the above reasons, we consider that these surveys do not provide reliable information.

The LFS 2002 ad hoc module on employment of disabled people includes a question on 'Time since onset of health problem or disability'. This might enable us to assess whether the mother was disabled or not before child birth. However, the ad hoc module does not present the exact number of years since onset of disability. The options for the answer are:

- 1. Less than 6 months
- 2. At least 6 months but less than 1 year
- 3. At least 1 year but less than 2 years
- 4. etc.

Consequently, we do not have sufficient information.

Another possibility is to use the national surveys on disability that include a question on the exact time of onset. But this does not solve the problem with dead children.

Available information does not enable us to estimate an accurate indicator.





#### III. CHOICE AND CONTROL

This part includes key areas of independent living and participation in the life of the community. The relevant articles of the UN Convention are notably, Article 19 (Living independently and being included in the community) and Article 29 (Participation in political and public life).

During discussion and consultation a certain number of indicators were selected. They focus on people with disabilities and cover the following items (with possible priority indicators shown in italics):

- 1. Proportion of disabled women and men who live in private households
- 2. Proportion of disabled people living in residential institutions
- 3. Expenditure on social support for disabled people to live at home
- 4. Expenditure on residential institutional provision for disabled people
- 5. Enough help with personal care and household activities
- 6. Home care services for disabled people
- 7. Number of people receiving personal or individual budgets for independent living (Administrative data)
- 8. Voting participation in general elections compared to general population
- 9. Active political participation
- 10. Proportion of disabled Parliamentarians

#### 1. Proportion of disabled women and men who live in private households

Ideally, we ought to be able to present the number of people with a disability living in private households or in institutions. However, the elaboration of such an indicator presents a certain number of problems which were discussed above.

Most available surveys with a question on disability (EU-SILC, Time Use Survey, ESS, EQLS, etc.) cover private households. Consequently, we can make a good estimate of people with disabilities in private households.

Eurostat provides the aggregated results on its website. EU-SILC annual data can be accessed by degree of disability, sex, age, educational level and income quintile. It is interesting to note that the EU-SILC reports 'self-perceived limitations in daily activities (Limitation in activities people usually do because of health problems for at least the last 6 months)'. This wording refers to past limitations although it could be improved by referring to limitations expected to last at least six months.







Figure 1: Percent of people living in private households declaring an activity limitation (16+), 2007





Source: Eurostat (EU-SILC)

The LFS 2002 ad hoc module on Employment of disabled persons covers people aged 16 to 64 years living in private households<sup>25</sup>. Disabled persons are those who stated that they had a longstanding health problem or disability (LSHPD). This survey presents also work limitations (regarding the kind of work or the amount of work, and mobility problems). The main tables can be found on Eurostat's website.

The LFS 2011 ad hoc module on employment of disabled people will present "Limitations in working activities" (AV.5 to AV.7) and distinguishes:

<sup>&</sup>lt;sup>25</sup> The survey was conducted in all the 15 old Member States of the EU as well as in 9 at that time acceding or candidate countries (Czech Republic, Estonia, Cyprus, Latvia, Hungary, Malta, Slovenia, Slovak Republic and Romania) and in Norway.





- 1. limitation in the number of hours that he/she can work in a week
- 2. limitation in the type of work (for instance, having problems in carrying heavy loads, working outdoors, sitting for a long time)
- 3. limitation in getting to and from work

The European Health Interview Survey (EHIS) includes the following question (HS.2): "Do you have any longstanding illness or [longstanding] health problem? [By longstanding I mean illnesses or health problems which have lasted, or are expected to last, for 6 months or more". The following question is (HS.3): "For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do"? The standardized European Health Interview Survey (EHIS) will better formalise and harmonise the whole approach in all Member States (except Luxembourg). The first round took place in the period 2007-2009. Before this period, available data cover 16 countries (15 EU Member States and Norway). However, sampling methods and the population covered varies across participating countries.

Furthermore, the EHIS survey asks "Do you usually have difficulty doing any of these activities by yourself"? (PC.1) with  $\cdot$  No difficulty  $\cdot$  Yes, some difficulty  $\cdot$  Yes, a lot of difficulty  $\cdot$  I can't achieve it by myself. The list of activities includes:

- 1. Feeding yourself
- 2. Getting in and out of a bed or chair
- 3. Dressing and undressing
- 4. Using toilets
- 5. Bathing or showering

This question focuses on restrictions of Activities of Daily Living (ADL) and defines 'dependency'.

Available data enable us to provide estimates according to different definitions of disability. It would therefore be interesting to provide different estimators of the number of disabled men and women living in private households based on:

- self-perceived limitations in daily activities (EU-SILC),
- work limitations (LFS ad hoc module), and
- dependency (EHIS).

It would be necessary to use different disability definitions for different indicator items (depending on the data that exists to support them). In this example, it may be possible to compare the effect of different disability definitions on the 'same' indicator.

# 2. Proportion of disabled people living in residential institutions

As noted above, most surveys cover people living in private households. However there are a number of surveys covering people in institutions. The inclusion of people in institutions in the survey samples presents some specific statistical issues (for example need to use a third person if the interviewee may not communicate, etc.).





The HIS covers private households but some countries include people in institutions. However, they concern mainly homes for elderly (Denmark, Finland, Malta, Slovakia and Sweden) while in others this extension is only partial (Belgium, Bulgaria, Czech Republic). Consequently, they don't include disabled children and adults in institutions.

A certain number of special surveys focussing on disability include people living in institutions, notably:

Austria: France :	'Microcensus Survey on Disabled' (1995); 'Disability and Health' ('Handicap Santé') took in two steps: first, the 'Household Disability and Health Survey' ('Enquête Handicap-Santé Menage') (2008) and second 'Institution Disability and Health' ('Handicap-Santé Institution') (2009). This survey updates the 'Survey on handicaps, disabilities and dependence' ('Enquête Handicap-incapacités-dépendance') (1998 & 1999);
Spain :	'Survey on Disabilities, Personal Autonomy and Dependency' (1999 & 2008). The survey includes two blocks (1. Encuesta dirigida a hogares, 2. Encuesta dirigida a centros);
Ireland:	'Survey of long-stay units/nursing homes' (2000);
Netherlands:	'Longitudinal Ageing Study Amsterdam' (LASA) (2005/2006);
Portugal: UK:	'National Survey on Impairments, Disabilities and Handicaps' (1995); 'Health Survey for England' (2000). The 'Survey on disability and care' provides a good methodology but is old (1985/6).

Certain countries exploit census data in order to estimate the number of disabled persons in institutions, e.g.:

HU: Census 2001. Disabled persons living in institutions;

UK: Census 2001. Limiting long-term illness data in the communal establishment population.

We may remind here the work done by the Washington Group. As noted above, it aims at guiding the development of a small set or sets of general disability measures, suitable for use in censuses, sample based national surveys, or other statistical formats, for the primary purpose of informing policy on equalization of opportunities.

Administrative registers are another source of data on disabled people living in establishments although these data are not comparable to data delivered by surveys. Administrative data often cover people who receive a disability related benefit. A certain number of countries publish the number of beneficiaries by age, sex, etc. including place of residence e.g.:

Germany: Persons with a need for long-term care (law on long-term care insurance); Luxembourg: Beneficiaries of long term care insurance;

In principle, all countries do include everyone in institutions in their census (and they distinguish a private house from an institution, prison, residential school, etc). However, not all countries include a question on disability in their questionnaire.

As many countries plan their next census for 2010/11, it might be useful to introduce a common question in the national questionnaires. However, the results might be poor. Census are not aimed and designed to meet the issues discussed in this report.





From another point of view, data concerning the number of persons in institutions are not always relevant for our purpose since not all residents are disabled people. However, this information might be useful for an estimate of people with disabilities in institutions.

Finally, TransMONEE Database provides data on children in Central and Eastern Europe and the Commonwealth of Independent States<sup>26</sup>. It is compiled by the UNICEF Regional Office for CEE/CIS and provides an annual estimate of children with disabilities in residential care. Most of the data are collected directly from National Statistical Offices, who complete and return to UNICEF IRC a standardized template. However, in recent years, UNICEF IRC has collected data for the Baltic States from the websites of the respective National Statistical Offices. Additional data are also obtained from other international organizations or are calculated by UNICEF IRC. Due to the different data sources related to some of the indicators, the data presented in the TransMONEE database may diverge from those presented in other UNICEF publications and databases.

Table 2: Number of children with disabilities in residential care, at the end of the year,2006

Czech Republic	Hungary	Poland	Slovakia	Slovenia
13.145	1.853	30.227	2.493	1.049
Estonia	Latvia	Lithuania	Bulgaria	Romania
464	602	4.228	3.025	7.100

Source: TransMONEE

We could combine the different sources and present a certain number of indicators. However, the results of the above surveys and administrative registers may raise comparability problems, although some countries use classifications which are close to ICIDH and ADLs (e.g. surveys in France and Spain; Census in Hungary).

The compilation of survey results and data from administrative registers may provide a proxy estimator for the proportion of disabled people living in residential institutions. However, this might raise comparability issues.

This conclusion relates to the whole of section 2 above, not only to the last example, which means that it would be possible to combine national data from a variety of different sources (although they might be very difficult to compare).

# 3. Expenditure on social support for disabled people to live at home

Eurostat publishes<sup>27</sup> annual social benefits for the function of 'Disability' by Member State. 'Care allowance' in euro can be isolated. Both periodic and lump sum payments are covered. At this we may add 'Assistance in carrying out daily tasks' which is reported as a benefit in kind. Another benefit in kind is 'rehabilitation'.

<sup>27</sup> The data are also available on Eurostat's website

<sup>(</sup>http://epp.eurostat.ec.europa.eu/portal/page/portal/eurostat/home)





<sup>&</sup>lt;sup>26</sup> <u>http://www.unicef-irc.org/databases/transmonee/2008/Tables\_TransMONEE.xls</u> The database covers notably: Czech Republic, Hungary, Poland, Slovakia, Slovenia, Estonia, Latvia, Lithuania, Bulgaria, Romania and other non-EU Member States.

The OECD Social Expenditure Database (SOCX) includes internationally comparable statistics on public and (mandatory and voluntary) private social expenditure at programme level. It covers 30 OECD countries for the period 1980-2005. The SOCX database presents public and mandatory private programmes by branch (1.Old age, 2.Survivors, 3.Incapacity-related benefits, 4.Health, 5.Family, 6.Active labour market programmes, 7.Unemployment, 8.Housing, and 9.Other social policy areas), type of expenditure (cash / in kind) and type of programme.

Expenditure may be estimated in euros and as a % of GDP. The amount of expenditure can be split into public and private expenditure. Of course, the indicator on public expenditure might be considered as a priority. However, OECD data do not cover all EU Member States<sup>28</sup>.

Social expenditure on services for disabled people encompasses services such as day care and rehabilitation services, home-help services and other benefits in kind. More specifically the data present:

- 1. Disability pensions
- 2. Residential care / Home-help services
- 3. Rehabilitation services
- 4. Day care / Home- help services
- 5. Supported employment and rehabilitation

Expenditure on Day care / Home help services is relevant here. For example, in Germany this covers:

- 1. Home-help services for disabled (Health insurance),
- 2. Home-help services for disabled (Social assistance)
- 3. Home-help services for disabled (Long term care insurance, since 1995)
- 4. Assistance in carrying out daily tasks for disabled (Occupational accident insurance)

But in Sweden, it includes Home-help for the disabled provided by local governments and Home-help for the disabled funded under other general national benefits.

The composition of expenditure is different across Member States and reflects different policies in favour of people with disabilities. This is clear for the countries chosen in our example.

An interesting question is whether we may estimate a measure of 'generosity' in the level of disability benefits. This could be done by dividing the total amount by the population of the same age group or the number of disabled people of the same age group.

<sup>&</sup>lt;sup>28</sup> OECD data cover: Australia, Austria, Belgium, Canada, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Spain, Sweden, Switzerland, Turkey, United Kingdom and United States.





Available data enable us to compute public expenditure for Day care / Home help services in Euros per capita and as a % of GDP (for 19 Member States).

It would also be interesting also to consider the number of persons on disability benefits, although there is a comparability problem between countries (e.g. to understand what is a 'disability' benefit in cash or in kind, in different countries). This is a slightly different indicator to the overall expenditure on social support described in this section<sup>29</sup>.

# 4. Expenditure on residential institutional provision for disabled people

As noted above, the OECD Social Expenditure Database (SOCX) includes internationally comparable statistics on public and (mandatory and voluntary) private social expenditure at programme level.

It presents expenditure for Residential care / Home-help services. However, in certain cases, we might not be able to distinguish between expenditure on accommodation and home help. This kind of expenditure includes for example in Germany:

- 1. Accommodation and assistance in carrying out daily tasks for old age (Occupational accident insurance)
- 2. Accommodation for disabled (Occupational accident insurance)
- 3. Accommodation for disabled (Long term care insurance, since 1995)
- 4. Accommodation for disabled (Social compensation, assistance to war victims)
- 5. Accommodation for disabled (Social assistance)

But in Sweden, it includes: 1.Accommodation for the disabled funded by local governments and 2.Accommodation for the disabled provided by county councils.

Available data enable us to compute public expenditure for Residential care / Home-help services in Euros and as a % of GDP (for 19 Member States).

# 5. Enough help with personal care and household activities

Ideally, we ought to identify:

- 1. the needs (number of people needing help and assistance for activities of daily living);
- 2. the supply of services (number of people receiving help and assistance for activities of daily living);
- 3. the financial resources affected to the fulfilment of these needs;
- 4. estimate of any gap between supply and demand.

APPLICA & CESEP & European Centre Final Report November 2007; Chapter 1





<sup>&</sup>lt;sup>29</sup> The number of persons in disability benefits according to different definitions and methods is discussed in Study of compilation of disability statistical data from the administrative

registers of the member states study financed by dg employment, social affairs and equal opportunities (CONTRACT NO VC/2006/0229 – EUR 363,268.42)

### <u>a. The needs</u>

The European Health Interview Survey (EHIS) reports activity restriction (limitation in usual activities because of a health problem) in the past 6 months as well as Activity limitations of Daily Living (ADLs). The EHIS is currently held every 5 years (but in some countries annually) and the latest round took place in the period 2007-2008.

For example, the UK Health survey reports limitations in activities of daily living (ADLs): getting in and out of bed or a chair, dressing, washing, eating and toileting. The Belgian Health survey asks about limitations concerning getting in and out of bed, getting up / sitting down, dressing/undressing, washing hands and face, eating and cutting food, going to the toilet, urinary continence, walking, hearing and seeing. It asks also about social participation restrictions (Instrumental Activities of Daily Living: IADLs).

Other surveys reporting ADLs are:

- Austria: 'Microcensus survey on Disabled'. This survey reports also IADLs,
- Germany: 'German Socio-Economic Panel' (GSOEP) and 'Microcensus' (module on care dependency in the framework of the long-term care insurance);
- France: Disability and Health' ('Handicap Santé');
- Spain: 'Deficiencies and Disabilities';
- UK: 'British Household Panel Survey'

Also the health module of Statistics Netherlands' 'Permanent Life Situation Survey' (POLS) includes three OECD mobility indicators.

#### b. Supply of help

The European Health Status Module (included in European Health Interview Survey – EHIS) contains the following question (PC.2): "Do you usually have help"? If YES the survey asks on "What type of help"? The answer covers:

- Personal assistance
- Technical aids
- Housing adaptation

A certain number of surveys present whether the person with an activity restriction receives care or assistance, notably:

- Austria (Microcensus);
- France (Handicaps-Disabilities-Dependencies survey);
- Poland (Health Care in Households);
- UK (General Household Survey; module on the elderly: 65+)

However, the reference period for care is not always the same (day, week or month). Also, it is important to note that data might overestimate the situation by asking about use of services in the last month. This means that persons with a temporary dependency who received care are included.





We have to distinguish these surveys from those questioning interviewed persons on the nature and amount of care <u>provided</u>. 'Care provided' is the standard question in time use surveys (e.g. Eurostat TUS) and surveys focussing on gender equality (e.g. the EQLS).

SHARE asks the following question: "Thinking about the activities that you have problems with, does anyone ever help you with these activities"? (PH050). The answer (1.Yes | 5.No) includes partner and other people in the household.

On the other hand SHARE asks: "Please tell me whether you have any difficulty doing each of the everyday activities on card ..." (PH048) and "Here are a few more everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional or memory problem" (PH049). The list is detailed and covers both Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).

However, the SHARE survey covers only people aged 50 years or more.

Consequently, we have all necessary information to estimate the number of elderly people needing help and the nature of limitations on ADLs and IADLs.

#### c. Supply and demand

The European Health Status Module (included in European Health Interview Survey – EHIS) contains the following question (HA.4): "Do you have enough help? Yes / No If No the survey clarifies" (HA.4.1) "What type of help you don't have enough"? and distinguishes:

- Personal assistance
- Technical aids
- Housing adaptation

Furthermore, SHARE asks whether "Would you say that the help you receive meets your needs? Possible answers are: 1.All the time; 2.Usually; 3.Sometimes; 4.Hardly ever" (PH051).

This gives an estimate of whether current supply meets (subjective) demand.

We can note that some national disability surveys report whether the disabled person considers that supplied support is sufficient (e.g. the Spanish 'Disabilities, Personal Autonomy and Dependency' (2008) covers technical aids for activities of daily living).

# <u>d. Formal /Informal help</u>

The SHARE survey puts the following question:

- "Did you receive in your own home any of the kinds of care mentioned on this card? The answers include (HC032): 1.Professional or paid nursing or personal care; 2.Professional or paid home help, for domestic tasks that you could not perform yourself due to health problems; 3.Meals-on-wheels; 4.None of these; and
- "Has any family member from outside the household, any friend or neighbour given you any kind of help listed on this card" (SP002)?
- "Is there someone living in this household whom you have helped regularly during ... with personal care, such as washing, getting out of bed, or dressing" (SP018)?





Furthermore, for each case SHARE presents detailed information on frequency, type of help, etc.

Consequently, we can estimate the number of disabled people receiving home care, informal care or both. However, an important limitation is that SHARE covers only people aged 50 years or more.

EHIS provides information on the number of disabled people by type of activity limitations. EHIS, National surveys (and SHARE) provide the number of disabled people receiving help. EHIS (and SHARE) provide an indication of the gap between supply/demand.

National surveys and SHARE present information on the type of help received, the nature of help (formal/informal), the frequency, and kinship between carer and person cared for.

#### 6. Home care services for disabled people

As noted above, Eurostat publishes annually data on social benefits by function<sup>30</sup> (benefits by function are included in the main ESSPROS tables and 'disability' can be separated from 'sickness and health' in this context.): disability, family/children, housing, old age, sickness/health care, survivors, unemployment and social protection.

The 'Disability function' covers benefits that:

- provide an income to persons below standard retirement age whose ability to work and earn is impaired beyond a minimum level laid down by legislation by a physical or mental disability;
- provide rehabilitation services specifically required by disabilities;
- provide goods and services other than medical care to disabled people.

Disability function includes cash benefits (periodic/lump sum), periodic care allowance, disability pension, early retirement, accommodation, home help and rehabilitation. These aggregates are further disaggregated as follows:

1. Cash benefits

Disability pension Early retirement benefit due to reduced capacity to work Care allowance Economic integration of the handicapped Other cash benefits

30

http://epp.eurostat.ec.europa.eu/portal/page/portal/living conditions and social protection/data/d atabase




2. Benefits in kind Accommodation Assistance in carrying out daily tasks Rehabilitation Other benefits in kind Expenditure- tables are further disaggregated into:

- lump sum and periodic benefits,
- means tested and non-means tested.

Countries covered are EU-27, Iceland, Norway, and Switzerland. The extractions can be performed in euro per inhabitant, by millions in euro/national currency/PPS, percentage of GDP and PPS per inhabitant.

Assistance in carrying out daily tasks includes practical help provided to disabled people to assist them

with daily tasks. Home help is included in this category, as well as the payment of an allowance to the person who looks after the disabled person. The database enables us to distinguish expenditure for home help and care allowances.

Euro per innab	itant (a	CONST			- /					
	BE	BG	CZ	DK	DE	EE	GR	ES	IT	LV
Non means-tested	10.4	1.5	1.9	132.5	41.9	1.1	1.3	:	0.0	0.5
Means-tested	:	:	:	:	5.3	:	:	1.8	2.9	:
means tested										
	L	1	L							
	LT	LU	NL	AT	РТ	RO	SI	FI	SE	UK
Non means-tested	LT :	<b>LU</b> 606	<b>NL</b> 0.0	<b>AT</b> 0.1	<b>PT</b> 0.0	<b>RO</b> 0.8	<b>SI</b> 0.0	<b>FI</b> 61.1	<b>SE</b> 261.4	<b>UK</b> 1.2

## Table 3: Home help (non means-tested and means-tested; all schemes), 2006 Euro per inhabitant (at constant 2000 prices)

Source: Eurostat. Data are provisional for certain countries.

This compares the number of Euros per year per person in the total population spent on this function. This kind of example could be used in indicator work, but would need to be added to with statistical notes and explanations of definition underneath.

Care allowance includes a benefit paid to disabled people who need frequent or constant assistance to help them meet the extra costs of attendance (other than medical care). The benefit must not be a reimbursement of certified expenditure, which would be classified as benefit in kind.

## Table 4: Periodic care allowance, 2006

Euro per inhabitant (at constant 2000 prices)

EU27	BG	CZ	DE	EE	ES	FR	IT	CY	LV
50.5	4.0	1.3	13.4	22.2	0.0	10.6	144	20.4	0.2
LT	AT	PL	РТ	RO	SI	SK	FI	SE	UK
3.2	38.8	8.2	4.1	0.2	12.5	2.1	19.6	38.9	212

Source: Eurostat. Data are provisional for certain countries.

Note: Lump sum care allowance is reported in 3 Member States and is extremely low.





Eurostat database reports expenditure on Home help and Care allowances per inhabitant.

Is it not possible to know the exact number of persons receiving help and care allowance in each member State. Examples are included in the ANED country reports on social inclusion and independent living<sup>31</sup>.

## 7. Number of people receiving personal or individual budgets for infependent living (administrative data)

Current policies favouring independent living of disabled people can be classified in two main categories.

The first favours the public provision of services at the relevant level (i.e. provision of services at local level). Continuity in the provision of these services is considered a priority. The second approach focuses on the right of a disabled person to choose the supplier of the desired service and to ensure a high quality for this service.

The second approach has led certain Member States to grant a specific budget to individuals instead of providing the same services through public organisations. From this perspective, the individual budget enables the beneficiary to buy the desired service on the market. The personal budget is under the control of disabled people.

This development has brought a significant 'noise' to available data. Certain Member States grant an individual budget, while other Member States provide similar services through local public services. For these reasons, we consider that the proposed indicator has to be interpreted with caution.

In addition, the risk of dependency is a new insurable risk in certain national systems. This risk is covered in a certain number of countries (e.g. Germany, Austria, Luxembourg, etc.) and is partly introduced or under study in other countries (e.g. Belgium). This insurance may generate a financial benefit which ought to be distinguished from the individual budgets as it derives from private insurance.

Also, individual budgets ought to be distinguished from invalidity pensions (contributory benefits) and disability allowances (social assistance / non-contributory schemes).

A summary of available statistics can be found in 'Study of compilation of disability statistical data from the administrative registers in the Member States' (Applica-CESEP- European Centre) (2007) financed by the EC.<sup>32</sup> Data have been collected for Austria, Belgium, Netherlands and Sweden but these data are not comparable and the efficacy of the scheme has been criticised.

<sup>&</sup>lt;sup>32</sup> <u>www.ec.europa.eu/social/BlobServlet?docId=3007&langId=en</u>





<sup>&</sup>lt;sup>31</sup> For example, in the UK, <u>http://83.244.183.180/5pc/is\_prim/tabtool\_is\_prim.html</u>

Available data cover a limited number of Member States and are not comparable. They come from administrative registers. Invalidity and disability pensions refer to disability insurance (contributory or not).

## 8. Voting participation in general elections compared to general population

The European Election Studies (EES)<sup>33</sup> are about electoral participation and voting behaviour in European Parliament elections. The European Elections Survey is organised at the same periodicity as the European elections (every five years). Also, it aims at identifying perceptions of and preferences about the EU political regime. Each EES survey has a thematic focus.

Additional components include content analyses of party manifestos and 'elite surveys' (candidates and MEPs). This survey does not include questions on disability. Also, concerning the economic status all inactive and retired are put together. However, some Member States (e.g. Belgium) distinguish 'incapacitated to work' but this is a very limited definition of disability.

The Comparative Study of Electoral Systems (CSES)<sup>34</sup> is a collaborative program of research around the world. Participating countries include a common module of survey questions in their post-election studies. The resulting data are reported along with voting, demographic, district and macro variables. The demographic variables (sex, age, race, etc.) do not include questions on disability.

The European Values Survey<sup>35</sup> includes the main domains of life: work and leisure time, family and sexuality, religion, politics and ethics. New issues in the third wave were solidarity, social capital, democracy, and work ethics. This survey includes notably a question on voting behaviour (Q75): "If there was a general election tomorrow, can you tell me if you would vote"? The next question focuses on which party. However, the EVS reports only the state of health (All in all, how would you describe your state of health these days? Bad / Good / etc.).

Finally, the EQLS survey includes an interesting question (Q21): "Some people don't vote nowadays for one reason or another. Did you vote in the last (country) national election held in (month/year)?

- Yes
- Yes, but I spoiled my ballot/left my ballot blank
- No"

As noted above, the EQLS survey contains also a question on disability.

The European Social Survey<sup>36</sup> includes a relevant question (B11): "Some people don't vote nowadays for one reason or another. Did you vote in the last [country] national election in [month/year]? Yes/No". The next question is focussing on "Which party did you vote for in that election" (B12)?

<sup>&</sup>lt;sup>36</sup> As noted above the ESS covers: AT, BE, BG, HR, CY, CZ, DK, EE, FI, FR, DE, EL, HU, IE, IS, LV, LT, NL, NO, PL, PT, RO, SK, SL, ES, SW, UK, CH, TR, RU, UKR.





<sup>&</sup>lt;sup>33</sup> <u>http://www.ees-homepage.net/</u>

<sup>&</sup>lt;sup>34</sup> http://www.umich.edu/~cses/

<sup>&</sup>lt;sup>35</sup> The last round (2005/08) included notably the following countries: BG, CY, FI, FR, DE, UK, IT, NL, PL, RO, SL, SP, SW, CH, TR, etc. European Values Study Foundation:

http://www.gesis.org/en/services/data/survey-data/european-values-study/

As noted above, the ESS survey contains also a question on disability.

The EQLS and ESS surveys enable us to estimate the percentage of people with and without disabilities who participate in the national election.

Disability questions ought to be included in the European Election Survey.

## 9. Active political participation

The European Social Survey (ESS) has a set of interesting questions (B13-B19) on active political participation, notably, "There are different ways of trying to improve things in [country] or help prevent things from going wrong. During the last 12 months, have you done any of the following? Have you...

- contacted a politician, government or local government official?
- worked in a political party or action group?
- worked in another organisation or association?
- Worn or displayed a campaign badge/sticker?
- taken part in a lawful public demonstration?
- Etc"?

Furthermore, the ESS survey asks (B21): "Are you a member of any political party"?

As noted above, the ISSP Leisure Time & Sports module mainly deals with leisure time activities. The question on social and political participation is made up of seven (7) items including participation in a political party or organisation. However, this survey covers only the general state of health.

Similarly, the European Values Survey contains a question on voluntary organisations and activities. It distinguishes membership of different structures, including: "Political parties or groups". However, this survey covers only the general state of health.

The ESS survey enables us to estimate the percentage of people with and without disabilities who worked in a political party or organisation.

Disability questions ought to be included in the European Values Survey.

## 10. Proportion of disabled parliamentarians

This indicator is similar to the one applied in the framework of gender equality.

The quota approach has received much attention in the Member States in the field of employment and training. However, one could raise a certain number of questions concerning its desirability and feasibility in the present field.





National and European associations (e.g. the European Disability Forum website) often report information on disabled parliamentarians.

However, these disabled parliamentarians generally have mobility or sensorial impairments, i.e. 'visible' disabilities, meaning that limiting chronic illnesses are not covered. The data therefore tend to be partial and cannot be compared across countries.

Also, it is questionable whether it is desirable for any person (whether elected or not) to declare a limiting chronic illness. In the framework of employment quotas, the beneficiary of the scheme counts if he is 'recognised' as a disabled person. Often employers report that disabled persons are reluctant to be categorised as disabled due to a risk of stigmatisation. A minimum level of comparability would require only parliamentarians who receive a disability-related benefit to be included.

In summary, available information is partial and not comparable across Member States.

Available data are partial and not comparable across Member States. it may be possible to obtain an overview of European Parliamentarians who receive a disability-related benefit and in certain countries parliaments publish income sources of their members but there are significant confidentiality issues.





## IV. ACCESS TO GOODS AND SERVICES

Accessibility to good and services by people with disabilities is considered as an important dimension of quality of life. Articles 9 (Accessibility) and 21 (Freedom of expression and opinion, and access to information) of the UN Convention are important here.

During discussions and consultations the following items were proposed (with possible priority indicators shown in italics):

- 1. How easy is it to use public transport?
- 2. Household access to a private car
- 3. Proportion of level access public buses/trains
- 4. How easy to get to local shops and services
- 5. Travel to work (measure to select)
- 6. *Key public websites meeting accessibility standards*
- 7. Key sectoral/commercial websites meet accessibility standards
- 8. Regular Internet usage compared to general population
- 9. Percentage national language subtitles from main public TV broadcasters
- 10. National language subtitles from main commercial TV broadcasters
- 11. Text access to main emergency telephone number
- 12. Audio description of programmes from main public TV broadcasters
- 13. Audio description of programmes from main commercial TV broadcasters
- 14. proportion of talking ATMs provided by main banks
- 15. Number of working sign language interpreters (e.g. per million population?)
- 16. Signed programmes from main public TV broadcasters
- 17. Signed programmes from main commercial TV broadcasters
- 18. Access and use of Information and Communications Technologies (ICT) (proposed by the author)

The conceptual issues in measuring barriers and environmental accessibility are key to the development of an indicator set, but the data to populate them is often not readily available. Some of the ICT examples are useful here because there are existing examples of pilot practice (e.g. it would also be useful to indicate the proportion of low-floor buses but the data is not made available).

#### 1. How easy is it to use public transport

A way to assess the facility/difficulty to use public transport is to compare its use by people with and without disabilities. However, in this comparison, we have to control for other variables e.g. income. From this perspective, the EDSIM asks "How frequently, if at all, do you travel as a passenger on any public transport nowadays? Daily, weekly, monthly, less than once a month, or never"?

Furthermore, the EDSIM includes the following questions:

"Do you use public transport

- as often as you want to or
- less often than you want to?





"What prevents you from travelling in public transport (more often)"?

- (1) Financial reasons
- (2) Too busy with work or family
- (3) No close public transport, no convenient route, not frequent enough, timetable unsuitable
- (4) A health condition, illness or disease
- (5) Some activity limitation such as difficulty in: seeing, hearing, communicating or concentrating or walking, going up steps, keeping one's balance, reaching, stretching, carrying or gripping.
- (6) Lack of space
- (7) Lack of personal assistance or help
- (8) Others reasons

The analysis of these answers gives some light on how easy it is to use public transport.

The SHARE survey asks "Would you say it (your area) has sufficient possibilities for public transportation? (HO057) 1. Yes | 5. No. As noted already the SHARE survey covers only people aged 50 or more.

The EQLS survey asks "In general, how would you rate the quality of each of the following PUBLIC services in our country? (Q56). As noted above it covers among others EU countries. The different items include:

- 1. Health services
- 2. Education system
- 3. Public transport
- 4. Child care services
- 5. Care services for elderly
- 6. Etc.

This provides an overall global evaluation for public transport.

Several countries have organised national travel or mobility surveys. However, disability appears only in a limited number of questionnaires, notably:

- 1. the UK National Travel Survey (NTS) (2006). The NTS asks people aged 16 and over whether they have difficulty going out on foot or using bus services. Those who say they have difficulties travelling on foot, by bus or both are classified as having mobility difficulties;
- 2. the UK survey on 'Attitudes of Disabled People to Public Transport' (2002) was run by MORI (Market & Opinion Research International) for Disabled Persons Transport Advisory Committee.
- 3. The Belgian 'Survey on mobility after 55' in Wallonia ('*Enquête sur la mobilité après 55 ans*') (2001) has questions on health and disability ;
- 4. The annual Dutch National Travel Survey enables us to draw some information on trips of people using transport for people with limited mobility.

The UK National Travel Survey<sup>37</sup> asks people aged 16 and over whether they have difficulty going out on foot or using bus services. This enables us to distinguish people with and without mobility problems. Those who say they have difficulties travelling on foot, by bus or both are classified as having mobility difficulties. According to the results:

<sup>&</sup>lt;sup>37</sup> Council of Ministers: EUROPEAN CONFERENCE OF MINISTERS OF TRANSPORT



- 1. the proportion of people with mobility difficulties increases greatly with age. This is the standard progression of disability (mobility) prevalence;
- 2. People with mobility difficulties make around a third fewer trips than those without difficulties.

The MORI survey asks:

- 1. "What types of disabilities do you have? (Visual, Hearing, Learning, Ambulant, Wheelchair users)";
- 2. What do you see as the main problems facing the area that you live in? Possible answers are: Transport, Housing, Health, etc. For information, the large majority says Transport.
- 3. Specific transport concerns include: difficulty in using public transport, frequency of public transport; etc.;
- 4. Another question focuses on satisfaction concerning different services and their quality notably local bus, local train, etc. In fact, section c of the questionnaire focuses on attitudes towards community transport and asks 'for each of the forms of transport you use, how easy or difficult do you find travelling by it"?

Consequently, it is important to insert a question on disability in national travel surveys in order to identify problems encountered by disabled people. When designing these surveys, we have to identify barriers that prevent people with severe learning disabilities accessing public transport and travelling independently.

A certain number of national disability surveys contain interesting information, notably:

- The French survey 'Health, Handicap and Word' ('Santé, Handicap et Travail') (2007) covers mobility problems. The 'Health Barometer' ('Baromètre Santé') (2005) covers means of transport but we cannot exploit the results as it refers only to health problems and not disability;
- The Spanish Survey of Disability, Personal Autonomy and Situations of Dependence' (*'Encuesta sobre Discapacidades, Autonomía personal y situaciones de Dependencia'*) (2008) treats accessibility, notably, problems with different types of transport.

The EDSIM module will presents detailed information on how easy it is to use public transport.

The EQLS survey provides a global evaluation for public transport by disabled and nondisabled people. As noted in previous sections, all major surveys enable us to distinguish chronic or long-standing limitations from temporary health problems.

Other available data concerning difficulties and satisfaction of using public transport cover either a restricted age group or a limited number of countries.

It is desirable to insert a question on disability in national travel/mobility surveys.

## 2. Household access to a private car

The EDSIM module includes the following questions:





- Do you (or anyone else in your household) have continuous use of a motorised vehicle (car, van, motorcycle, scooter or moped)?
- Do you yourself drive this vehicle?
- How frequently, if at all, do you drive this vehicle nowadays?
- How frequently, if at all, do you travel as a passenger in this vehicle nowadays?
- Do you go out in this vehicle(s)...
  - (1) as often as you want to or
  - (2) less often than you want to?
- What prevents you from going out in the household motor vehicle(s) (more often)?
  - (1) Financial reasons (General vehicle costs insurance, tax, fuel, road charges)
  - (2) Too busy with work or family
  - (3) Vehicle not always available
  - (4) A health condition, illness, injury or disease
  - (5) Some activity limitation such as difficulty in: seeing, hearing, communicating or concentrating or walking, going up steps, keeping one's balance, reaching, stretching, carrying or gripping.
  - (6) Vehicle lacks special adaptations
  - (7) Lack of personal help or assistance
  - (8) Others reasons

The last two questions present interesting information on access to a private car.

In the block of non-monetary household deprivation indicators, the EU-SILC survey asks 'Do you have a car? (HS110)

- 1. yes
- 2. no cannot afford
- 3. no other reason

The answer 'no-other reason' might include problems related to technical aids and necessary adaptations since the second answer refers exclusively to monetary constraints.

The SHARE survey asks "How many cars do you and your husband/wife/partner own? (AS049).

The EDSIM and EU-SILC survey enables us to estimate the number of people with and without a disability who have a private car and the percent who face barriers in its use.





## 3. Proportion of level access public buses/trains

In 2002 the International Association of Public Transport (UITP)<sup>38</sup> carried out a survey of 19 transport authorities or companies in major cities to find out their progress towards achieving accessible public transport. The respondents had to answer the following questions:

- 1. What proportion of low-floor vehicles do you have in your current fleet? (%)
- 2. What proportion of low-floor vehicles do you purchase in new vehicle orders?

This survey reports the number and the percentage of low-floor buses in fleet (2001) in participating cities. It provides also information on the type of ramps, bus stations, etc.

The UK National Travel Survey (2006) asks people aged 16 and over whether they have difficulty going out on foot or using bus services. Also, the UK survey on 'Attitudes of Disabled People to Public Transport' (2001/2002) includes notably questions aiming at identifying expectations from public transport, what disabled people consider are the priorities for improving public transport and what deters disabled people from using public transport. As noted above, the MORI survey asks about satisfaction concerning different services and their quality notably local bus, local train, etc. The availability of comparable national transport surveys and data is surprisingly lacking at the moment.

It might be useful to insert questions concerning disability in national travel and mobility surveys. This could encourage Member States to collect data which are necessary for the monitoring of the accessibility and mobility policies.

In the private sector, we may note the survey on 'Accessible Taxis' which presents the percentage of wheelchair accessible taxis in national taxi parcs<sup>39</sup>.

Available data buses are relatively old<sup>40</sup> and cover a limited number of countries. Member States could insert disability questions in their national travel and mobility surveys.

## 4. How easy to get to local shops and services

The EDSIM module includes the following question: "How often do you leave your home"?

- (1) Frequently, everyday or almost everyday
- (2) Sometimes, at least once a week
- (3) Seldom, less than once a week
- (4) Never
- "What prevents you from leaving your home (more often)"?

http://www.internationaltransportforum.org/europe/ecmt/pubpdf/07TaxisE.pdf#search="disability" <sup>40</sup> But see, http://www.officefordisability.gov.uk/docs/res/annual-report/indicators/f1.pdf





<sup>&</sup>lt;sup>38</sup> <u>http://www.internationaltransportforum.org/europe/ecmt/pubpdf/04Access.pdf#search="disability.</u> The survey covered in particular: NL, ES, HU, DE, DK, CH, UK, FR, CZ, IT, SE, AT, BE (W).

<sup>&</sup>lt;sup>39</sup> The survey covered: Austria, Belgium, Bosnia & Herzegovina, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Luxembourg, Netherlands, Norway, Poland, Portugal, Slovakia, Spain, Sweden, Ukraine and UK. Data are not available for all countries. European Conference of Ministers of Transport & International Road Transport Union;

- (1) Financial reasons/lack of money
- (2) Too busy with work or family
- (3) Unsuitable surroundings (too many hills, slopes, steps, uneven surfaces, slippery paths or pavements. No resting places)
- (4) A health condition, illness or disease
- (5) Some activity limitation such as difficulty in: seeing, hearing, communicating or concentrating or walking, going up steps, keeping one's balance, reaching, stretching, carrying or gripping.
- (6) Lack of mobility equipment
- (7) Lack of personal help or assistance
- (8) Lack of convenient or available transport
- (9) Lack of adequate signs and information
- (10) Do not want to or need to leave home more often
- (11) Other reasons

Analysis of the different options, in particular option (3) of the second question, may provide useful information.

Other questions ask for example:

- "Thinking about all the buildings that you need to visit public buildings, offices, shops, and people's homes. How often do you have difficulty getting to all the buildings that you want to, that is from your home to the front door of those buildings"? and
- "How often do you have difficulty getting through all the buildings that you need to, for example across a department store or a supermarket"?
- "How often do you have difficulty using the facilities in all the buildings that you go to, for ex. using the toilets, purchasing items over the counter, getting from one floor to another":
  - (1) very often
  - (2) quite often
  - (3) occasionally
  - (4) or never?

This helps us to estimate the number of people who face barriers (difficulties) as well as the grade of this difficulty (very often, etc.) and compare it with non-disabled people. In order to focus on disability and not age, we have to control for age.

The EQLS survey asks a question which is not exactly what we are searching for but could be helpful. The question is "are there any of the following facilities available within walking distance ... in your immediate neighbourhood? (Q55): a. A food store or supermarket; b. Post office; c. Banking facilities; d. Public transport facilities (bus, metro, tram, etc) etc.

Several other national surveys adopt an approach based on 'geographic distance'. Questions on barriers restricting accessibility are scarce. Certain national surveys treat accessibility of services, notably:





- the Belgian 'Survey of mobility after 55 years in Wallonia ('*Enquête sur la mobilité après 55 ans en Wallonie*') (2001) studies the evolution of patterns concerning shopping. In this survey, we can distinguish disabled and non-disabled people.
- the French 'Baromètre CSA Opinion' (2002) asks all persons : "Are living and mobility conditions of disabled people easy, difficult, ... "? Other questions cover accessibility of shops, transport, etc.

Finally, an international survey studies accessibility of taxis. It presents the percent of Wheelchair Accessible Taxis in National Taxi Parcs<sup>41</sup>.

The EDSIM will provides the percent of disabled people who face barriers (different types) by disability status and age group.

## 5. Travel to work (measure to select)

The LFS 2002 ad hoc module asks all about the "Existence of a longstanding health problem or disability" (220) and if the answer is positive it asks "Whether health problem restricts mobility to and from work that can be done".

The LFS 2011 ad hoc module on employment of disabled people asks "The health condition(s) or disease(s) or difficulty(ies) is/are related to the person's limitation in getting to and from work"? Yes/No (AV7). Furthermore, it asks the "Main reason for limitation in work (... getting to and from work) that is not related to longstanding health conditions/diseases or basic activity difficulties". "Lack or poor transportation to and from workplace" is an option among different answers (AV8).

The wording of the ad hoc module 2011 might create confusion. It has to be clarified, notably in the different translations. The respective roles of impairments and contextual factors are not clear.

The Time Use Surveys<sup>42</sup> (2008 guidelines) ask "Do you have any chronic physical or mental health problem, illness or disability"? (I31) and "Are you hampered in your daily activities by this physical or mental health problem, chronic illness or disability"? (I32)

These surveys cover transport mode and timing. Also, they present information by travel purpose. Consequently, the Time Use Surveys enable us to compare time spent to and from work between disabled and non-disabled people.

When comparing average time for certain activities, we have to take into account that mobility problems may push disabled people to find a job close to their house with an associated reduction of choices. This means that comparing average time for travel to work might lead to erroneous conclusions. It is better to estimate time per kilometre each time this is possible.

http://www.internationaltransportforum.org/europe/ecmt/pubpdf/07TaxisE.pdf#search="disability" <sup>42</sup> The Time Use Surveys cover: BE, DK, DE, EE, ES, FR, IT, LV, LT, HU, NL, PL, SI, FI, RO, SE, UK plus Norway.





<sup>&</sup>lt;sup>41</sup> European Conference of Ministers of Transport & International Road Transport Union. The survey covers: Austria, Belgium, Bosnia & Herzegovina, Czech Rep, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Luxembourg, Netherlands, Norway, Poland, Portugal, Slovakia, Spain, Sweden, Ukraine & UK.

Certain surveys ask about mobility problems and distinguish between difficulties in everyday life and in relation to work (including moving around the work place) (e.g. the French survey 'Santé, Handicap et Travail' (2007)).

The process of asking first if the person has a mobility problem and then if this problem restricts mobility to and from work is not desirable. In fact, it does not take into account architectural barriers which push people into inactivity or limit the array of possibilities offered to unemployed disabled. Consequently, the question related to travel to and from work ought to take into account problems encountered by unemployed and inactive disabled. Architectural elements might be an important barrier pushing them out of the labour market.

The relevant question ought to be formulated in accordance with the economic status, e.g. "Do you have any mobility problems which affect:

- for the unemployed: chances to find a job;
- for the inactive: employment options; and
- for working people: the nature of work you can do or chances to keep your job.

The LFS ad hoc modules present the percent of people who declare: 'Lack or poor transportation to and from workplace'.

The Time Use Surveys enable us to compare average time spent to and from work between disabled and non-disabled people.

## 6. Key public websites meeting accessibility standards

One of the most innovative components of the Convention on the Rights of Persons with Disabilities relates to dispositions concerning ICTs – Information and Communications Technologies - both from a digital accessibility and assistive technologies standpoint. This approach has fostered several initiatives in this direction.

At a global level, G3ict, the Global Initiative for Inclusive Information and Communication Technologies, is a flagship advocacy initiative of UN-GAID, the United Nations Global Alliance for ICT and Development.

Initiated in December 2006 by W2i, the Wireless Internet Institute, G3ict is a public-private partnership dedicated to facilitating the implementation around the world of the Digital Accessibility Agenda defined by the Convention on the Rights of Persons with Disabilities<sup>43</sup>. They have also developed a document on indicators with an accessibility index.

Measuring Progress of eAccessibility in Europe (MeAC) is a study covering EU 25 Member States and three reference countries (US, CA, AU).

<sup>43</sup> <u>http://g3ict.com/about</u>





The MeAC project<sup>44</sup> conducted a web accessibility test across a number of websites in July 2007. The websites to be tested were classified into two domains:

- Governmental websites, including the main web portal of the national government and the website of the national parliament as well as of several national ministries (social affairs, health, education, employment/labour, as applicable).
- Private / sectoral websites, including the website of the main national daily news paper, the main free-on-air broadcasting TV channel, the main national retail bank, the main national railway service and the main national operator for mobile and fixed-line telecommunication, respectively.

MeAC notes that "eAccessibility" concerns the design of Information and Communication Technology (ICT) products and services so that they can be used by people with disabilities, whether of a permanent or temporary nature, and by older people with age-related changes in functional capacities.

All websites underwent an automated accessibility test. The survey constructs an indicator named: Basis accessibility of governmental websites (WCAG Level A automatic checkpoints only). It presents the Share of governmental websites included in the test which are accessible according to Web Content Accessibility Guidelines, Level A [Score = % of websites passing automatic test].

The MeAC project presents an assessment for a specific year and the update for a limited number of countries. The reported data are based on a small number of websites but considered as a representative sample. They are more pilot indicators rather than widely accepted quantitative indicators, but they fill a gap where data are scarce.

It might be desirable to provide an overall indicator including both public and private websites. The same service might be supplied by a public body in one country and by a private organisation in another country.

The reported data are based on a small number of websites but considered as a representative sample.

MeAC presents the percentage of governmental websites passing accessibility test. This indicator could be combined with the next one.

There remains no real basis for large-scale statistical indicators of web site accessibility in different coutnries (MeAC only checks a small number of key sites because there is no large

<sup>&</sup>lt;sup>44</sup> MeAC - Measuring Progress of eAccessibility in Europe: Assessment of the Status of eAccessibility in Europe, October 2007 (Main Report, Annexes and Follow up 2008). The survey covers EU 25. The eAccessibility status situation was revisited in ten countries in 2008 as follows: • Austria • France • Germany • Ireland • Italy • Portugal • Spain • Sweden • The United Kingdom • The United States of America. Data on the indicators used was gathered during the summer of 2008 through two different methods: 1) National-level data gathering on indicators relating to telephony, television, computing and self-service terminals in each country by a network of national correspondents; 2) Systematic assessment of the accessibility of a sample of key public and private websites by a team of experts within the core study team, including both automatic and manual testing. <u>http://www.eaccessibilityprogress.eu/country-profiles/</u>





scale data set or testing)

It would also be relevant to consider measures of difficulty in using the Internet.

## 7. Key sectoral/commercial websites meet accessibility standards

The MeAC project (see above) presents an indicator named: Basis accessibility of private/sectoral websites (WCAG Level A automatic checkpoints only). It measures the share of private/sectoral websites accessible according to Web Content Accessibility Guidelines.

As noted above, private / sectoral websites, include the website of the main national daily news paper, the main free-on-air broadcasting TV channel, the main national retail bank, the main national railway service and the main national operator for mobile and fixed-line telecommunication, respectively.

Index values are standardized in order to allow comparison across domains and with policy achievements.

MeAC presents the percentage of websites passing accessibility test (Level A). This indicator could be combined with the previous one.

## 8. Regular Internet usage compared to general population

There is an important number of European and national surveys focussing on the use of internet at home. Among those which include a question on disability, we may note the following European surveys:

- Time Use Survey: Use of computers and the internet;
- EDSIM: The questionnaire comprises one section on 'Access to and use of Internet';
- EQLS: It contains questions concerning the use of internet;

Consequently, we may present the number of disabled and non-disabled people using internet at home.

The time use surveys enable us to estimate the time spent on internet. Also, the EQLS enables us to assess the regularity. A question (Q 51) asks "Which of the following best describes your use of the internet over the past month?

- Used the internet every day or almost every day
- Used the internet a couple of times a week
- Used the internet occasionally (once a month or less)
- Did not use the internet at all".

Certain surveys distinguish access, effective use and barriers. The EDSIM includes the following questions:





- Do you have access to the Internet from home?
- Do you use the Internet at home for any reason?
- Do you use the Internet from any other place (work, internet cafes, hotels, school or college) for any reason?
- Would you like to use the internet (more than you do at present)?
- What are the main reasons preventing you from using the internet (more)?

   (1)Financial reasons, (2) Too busy with work or family, (3)Lack of knowledge: don't know how to get or use internet, (4)A health condition, illness, or disease, (5)Some activity limitation such as difficulty in seeing, concentrating, reaching or gripping;
   (6)Lack of special aids or equipment; (7)Lack of personal help or assistance, (8)Other reasons

The analysis of these answers might help us to identify the nature of barriers.

Current surveys enable us to present the percentage of disabled and non-disabled people using internet in private households. We may also estimate the periodicity of use.

## 9. Percentage national language subtitles from main public TV broadcasters

MeAC notes that in the case of television, the basic eAccessibility yardstick is the extent to which disabled people (in so far as is technologically possible) have access to and can enjoy the same choice of programming as everyone else.

The MeAC study presents the average percentage of national language broadcasts (by the two main public broadcasters across the Member States) in 2006 which are subtitled in order to ensure that they are accessible for people with hearing impairments. More specifically, it presents the proportion of programmes broadcasted free on air with access services by the two main public broadcasters (in % of the overall programme broadcasted in 2006):

- 1. Any broadcast with subtitling,
- 2. Proportion in overall programming, and
- 3. Proportion in national language programming.

The MeAC study presents the percentage of national language broadcasts across Member States which are subtitled in order to ensure that they are accessible for people with hearing impairments.

This indicator could be combined with the next one.

## 10. National language subtitles from main commercial TV broadcasters

The MeAC study presents the average percentage of national language broadcasts by commercial channels which are subtitled in order to ensure that they are accessible for people with hearing impairments (see above for public TV broadcasters).





As before, it might be desirable to provide an overall indicator including both public and private broadcasters. The same service might be supplied by a public body in one country and by a private organisation in another country.

The MeAC study presents the average percentage of national language broadcasts from commercial channels across Member States which are subtitled in order to ensure that they are accessible for people with hearing impairments.

This indicator could be combined with the previous one.

## 11. Text access to main emergency telephone number

The MeAC study notes that in the case of telephony, the basic eAccessibility yardstick is 'functional equivalence', whereby disabled people have access to the same level and quality of everyday telecommunications services.

The MeAC study indicates the availability of text telephone relay services in Member States as well as facilities in place to enable text telephone users direct access the emergency telephone number. It presents a scoring system based on the analysis of national policies and laws. Also, the study retains access to emergency services by dialling 112 or another number.

MeAC assesses text relay service provision (video relay) per country by using in particular the following criteria:

- 1. Fully-up and running services
- 2. Accessible without additional service fee
- 3. 24h / 7 days relay service availability
- 4. Hours available on working days (if not 24/7)
- 5. Hours available on weekend (if not 24/7).

The MeAC survey asks "In your country, can the emergency services number(s) be contacted by text telephone and/or other forms of text communication"? (Q47). Also:

- 1. Please estimate how commonly video telephony is used by people in your country whose main language is sign language (Q54).
- 2. Is there a video telephone relay service operating in your country (i.e. a service that enables video telephone users to communicate with voice telephone users via an operator / interpreter, and vice versa) (Q55)?
- 3. In your country, can the emergency services number(s) be contacted by sign language users via videophone (Q56)?
- 4. Over the last 5 to 10 years, do you feel that any progress has been made in the availability of video telephony for sign language / lip-reading users in your country (Q57)?

These questions might be included into a survey and put to disabled people themselves. The existence of a service does not imply satisfaction by the target group.





The MeAC study has proposed an indicator summarising the availability of text access to main emergency telephone number which needs further testing.

The set of questions could be inserted into a questionnaire with the necessary adaptations.

## 12. Audio description of programmes from main public TV broadcasters

The MeAC study discusses audio description for people with visual impairments. Accessibility might include provision of speech, audio or other output modes as alternatives to visual displays. This provision of an additional audio channel / track could narrate the visual content in TV broadcasts.

The MeAC study presents the number of public broadcasters in Member States which provide any of their programmes with audio description (for visually impaired people) in 2006 and, some indication concerning the percentage of the overall programming. More specifically, it presents the proportion of programmes broadcasted free on air with access services by the two main public broadcasters (in % of the overall programme broadcasted in 2006):

- 1. Any program with audio description, and
- 2. Proportion in overall program.

As noted above, the distinction public – private TV broadcaster may lead to comparability problems across Member States. Consequently, it would hence be interesting to combine the present indicator (public TV) with the next one (commercial TV).

Furthermore, we might combine indicators covering language subtitles with indicators covering audio facilities. Although specific indicators are valuable for the study of specific groups, we risk arriving at a situation where we have to present each indicator by type of limitation (hearing, seeing, learning, etc.). It is instead desirable to construct a weighted indicator where the weights might be for example the relative demographic importance of each specific group.

The MeAC study provides the number of public TV broadcasters in Member States which provide any of their programmes with audio description.

It would be interesting to further test the MeAC approach and construct a global weighted indicator covering sub-titles, signing and audio facilities in both public and private TV broadcasters.

## 13. Audio description of programmes from main commercial TV broadcasters

Similar information is provided for commercial broadcasters as for public TV broadcasters (see above).

We may note the same comments as before.





The MeAC study provides the number of main commercial TV broadcasters in Member States which provide any of their programmes with audio description.

It would be interesting to further test the MeAC approach and construct an overall weighted indicator covering sub-titles, signing and audio facilities in both public and private TV broadcasters.

## 14. Proportion of talking ATMs provided by main banks

The MeAC study notes that in the banking sector, automated teller machines (ATMs) are designed to meet the needs of people with visual impairments. Usually referred to as 'talking' ATMs, such machines have a voice output option via headphones and/or external loudspeaker. They enable self-service for customers with visual impairments and are an important facility promoting equal access to banking services.

The MeAC study presents an indicator named: 'Deployment of talking ATMs by selected national retail banks'. It estimates:

- 1. Number of all ATMs deployed, and
- 2. Share of talking ATMs deployed by each main national retail bank as share of all ATMs deployed by the bank [Score: % of accessible ATMs]

The MeAC study provides the average proportion of talking ATMS installed by two main retail banks by Member State.

## 15. Number of working sign language interpreters (e.g. per million population)

Professional Interpreting Services is a pre-requisite for equal participation of deaf people in society.

Maya de Wit presents estimates<sup>45</sup> of the number of sign language interpreters in Europe. These estimates are based on a 2007 survey that was held among 30 national organizations of Sign Language interpreters (or associations of the Deaf) in 27 European countries.

The World Association of Sign Language Interpreters (WASLI)<sup>46</sup> notes that the numbers indicate the interpreters that are officially registered at certain associations. The number of interpreters working as freelancers not connected with the associations remains unknown. Interpreters not registered at the associations are mainly part-time interpreters combining their fulltime employment as teachers, clerks, etc. with working for the Deaf community.

The number of registered sign language interpreters could be compared to the number of deaf people (or people with severe hearing limitations). This latter number could be drawn from the EHIS survey.

<sup>&</sup>lt;sup>46</sup> http://www.wasli.org/PDFs/News/WASLI2007Issue3.pdf





<sup>&</sup>lt;sup>45</sup> Maya de Wit: 'Sign Language Interpreting in Europe', 2008 (English)

We may estimate the ratio of the number of registered sign language interpreters to the number of people.

## 16. Signed programmes from main public TV broadcasters

The MeAC study presents an estimate concerning to what extent public TV programmes with sign language interpretation are available in each country.

It reports in particular:

- 1. Any program with signing
- 2. Proportion in overall program

As noted above, it might be interesting to construct a global indicator covering subtitles, signing and audio facilities for both public and private broadcasters.

In the event that some disaggregation is considered desirable, we can present estimators for subtitles and signing separately.

The MeAC study provides the proportion of broadcasts with signing in overall programming.

It is desirable to construct an overall indicator covering subtitles, signing and audio facilities for both public and private broadcasters. If necessary, we can also present an estimator for subtitling.

## 17. Signed programmes from main commercial TV broadcasters

The MeAC study presents an estimate of the availability of commercial TV programmes with sign language interpretation in each country.

The same comments noted in the previous point apply here.

For information, we may note that MeAC presents the eAccessibility status according to the MeAC compound indicator set (2007, 2008) comprising:

1. Telephony

Telecom operators provision of accessibility information

Availability of text relay service

2. TV

Share of national language broadcasts with subtitles by two main public broadcasters

Share of national language broadcasts with subtitles by two main commercial broadcastersComputer

Hard- and software manufacturers provision of accessibility information

4. Web

Basis accessibility of governmental websites

Basic accessibility of private / sectoral websites

5. Self-service terminals

Deployment of accessible cash dispensers





The indicator covers 2007 and 2008 for certain countries and helps us to give an overall assessment of change over time.

The MeAC study provides the proportion of signed broadcast in overall programming of commercial broadcasters.

It is desirable to construct an overall indicator covering subtitles, signing and audio facilities for both public and private broadcasters. If necessary, we can also present an estimator for subtitling.

The items considered in the section above are heavily reliant on MeAC, which is not a recurrent survey. There would be a strong case for compilation of key data from national sources in future years (e.g. from public broadcasters etc).

## 18. Access and use of information and communications technologies (ICT)

Statistics on Information and Communications Technologies (ICT) is an annual survey<sup>47</sup>. It covers access to and use of ICT systems by individuals and/or in households, use of internet for different purposes by individuals and/or in households, ICT security, ICT competence, barriers to use of ICT, perceived effects of ICT usage on individuals and/or on households. However, not all subjects are covered each year.

It is desirable to insert the Minimum European Health Module (MEHM) in the next surveys. This will enable us to identify differences among disabled and non-disabled in a great variety of fields (use of ICT, ICT competences, barriers, etc.). Several of these aspects are not covered by the MeAC project.

We ought to insert the Minimum European Health Module in ICT surveys, although there would be concerns about the small sample representation of disabled people in such surveys (one possibility would be to promote over-representation with survey design to ensure adequate representation of disabled persons).

Another possibility would be to use household access to the Internet (which appears in some social surveys, for example).

<sup>&</sup>lt;sup>47</sup> From 2002 it is organised on an annual basis in the EU member states plus Norway, Turkey and Switzerland.





## V. EDUCATION AND LIFELONG LEARNING

Article 24 of the UN Convention (Education) is important here.

During discussion and consultation the following items were proposed (with possible priority indicators shown in italics):

- 1. Proportion of school-age disabled children attending mainstream schools
- 2. Disabled children of compulsory school age not enrolled in school
- 3. Pupils attending special schools
- 4. Educational attainment at school of disabled people (measure to select)
- 5. Early disabled school leavers
- 6. Degree/level qualification of disabled people compared to general population
- 7. Disabled students in higher education
- 8. Highest level of qualification of disabled people
- 9. Participation rate in life-long learning of disabled people
- 10. Participation in government training scheme by disabled people
- 11. Transition from school to work of young disabled (proposed by the author)

#### 1. Proportion of school-age disabled children attending mainstream schools

#### The number of disabled pupils

As noted above, surveys including children are very limited and pose serious problems of comparability. Data is therefore drawn from administrative registers.

Administrative data report the number of children and young people with special education needs (SEN) in mainstream schools. This raises two questions. First, there is no common definition of SEN in the Member States and secondly, the term 'mainstream' may cover different schemes.

The most frequently categories used for special educational needs include the following disabilities: psychological (psychic) and behavioural; sensorial (e.g. visual, hearing); physical; intellectual; learning; social; immigrants and minorities; travellers. All Member States refer expressly to children with psychological, intellectual, sensorial and physical impairments.

The data might be biased by a wide definition of SEN, in particular by a broad definition of 'learning difficulties'. However, this can be controlled since the majority of the Member States report the nature of the disability. Also, the same data often distinguish disabled children, travellers, minorities, etc. It is therefore possible to select only disabled children from the available data.

The term 'mainstream' may have a broad meaning in some countries due to the absence of a clear separation between 'special' and 'ordinary' programmes, particularly when policies aim to establish bridges between the two systems. In general we have enough information to assess the extent of comparability issues arising from these factors, but administrative registers need some preparation before they are used.





#### The number of disabled children

As noted in the introduction on 'Disability rates/Demographics' and in Part II, we can only produce an estimate of the total number of disabled children. Generally, surveys do not cover children. An alternative could be to use administrative registers, as all Member States grant a disability-related benefit to disabled children. It is hence sufficient to estimate this number from registers or use the OECD database on recipients of disability-related benefits. This indicator might be smaller than estimates based on surveys, since some disabled children might not benefit from a disability allowance.

However, the use of the total number of recipient children, as a base for comparison, might cause serious comparability issues across Member States. In fact, countries with very restrictive schemes will have a relatively small number of recipient children. Consequently, the ratio (children with SEN in mainstream / recipient children) will be very high in these countries sending a wrong message.

#### <u>The ratio</u>

Given the above noted problems, we consider that it is better to estimate: Children with SEN in ordinary education as a % of students in compulsory education. This will reduce statistical bias.

An alternative could be the number of children with SEN in ordinary education as a percent of the total number of children of the same age group. However, a certain number of national factors might affect similarly the behaviour of both disabled and non-disabled children (national social factors may explain low school enrolment for both disabled and non-disabled children). In the context of a European comparison, this indicator might provide confusing results. Countries with a low school participation rate for both disabled and non-disabled children would turn an overall low school participation problem into a discrimination issue. Consequently, as we want to identify any discrepancy between disabled and non-disabled children, we propose to use the ratio of Children with SEN in ordinary education as a % of students in compulsory education.

Furthermore, most countries report the sex (girls/boys). Since, available data indicate an under representation of girls, it might be useful to include the sex distribution for these countries.

The study 'Compilation of disability statistical data from the administrative registers of the Member States' (2007) by APPLICA & CESEP & EUROPEAN CENTRE presents a summary of administrative data<sup>48</sup>. In order to arrive at comparable data (at least to some extent) it was necessary to correct for age, nature of disability, type of school, etc. This disaggregation of disabled children is not routinely produced by the European Agency (EASNE), which uses simplified standardised reporting (e.g. for the number of children, the number in special schools) but the data is limited and incomplete<sup>49</sup>.

<sup>48</sup> <u>http://ec.europa.eu/social/main.jsp?catId=429&langId=en&moreDocuments=yes</u>

<sup>&</sup>lt;sup>49</sup> www.european-agency.org?country-information









<sup>1</sup>: Compulsory education ranges generally from 5/6 to 15/16 years old except in Belgium, Italy and Lithuania where it continues till 18 years. \*: Data might include pre-primary level.

Note: EE and LT use a large definition of learning, speech and communication problems. EU is a simple average of national percentages. Source: see text.

The alternative could be to indicate children with SEN in ordinary education as a % of all children with the same level of needs. This could help us to show the proportion of disabled children in mainstream and in special schools.

The group of disabled children is not a homogenous group. Information concerning the nature of disability/special education need is important for the formulation of relevant policies. Current data are not comparable. A certain kind of comparability could be achieved if we present them in very broad groups (e.g. psychic/psychological, intellectual, sensorial and physical impairments). This gain in comparability is at the expense of useful information concerning the type of disability / special education need. Consequently, efforts ought to be developed to harmonise existing classifications.

The sources of the above-mentioned study include in particular:

- Eurybase, the information database on education systems in Europe;
- EADSNE (European Agency for development of special need in education);
- UNICEF,
- OECD, and
- National Ministries of Education.

Administrative registers permit us to estimate the number of children with SEN (and possibly disaggregated by disability) in mainstream schools as a % of pupils in compulsory education; We may estimate this indicator by sex (girls/boys). This was also discussed in the Applica/SESEP report (chapter II).

We ought to harmonise existing administrative classifications concerning the type of disability / special education need.





## 2. Disabled children of compulsory school age not enrolled in school

In order to be able to construct this indicator, we need to know:

- the number of disabled pupils, and
- the total number of disabled children.

As noted in the introduction on 'Disability rates / Demographics' and in Part II, we can only produce estimates of the number of disabled children. The alternative method could be to use administrative registers. In fact, all Member States grant a disability related benefit to disabled children. We would just need to estimate this number or use the OECD database on recipients of disability related benefits. It is important to note that this indicator might be smaller compared to estimations based on surveys, since some disabled children might not benefit from a disability allowance.

The total number of disabled pupils could be constructed by adding pupils in mainstream education and in special education. The first, has been discussed above, the second will be discussed below.

One might think that coherence requires to use the ratio of pupils with SEN to the total number of children (same age group) receiving a disability related benefit. In fact, both come from administrative registers. However, we have to note that the number of recipient children might cause serious comparability issues across Member States. In fact, countries with very restrictive schemes produce a relatively small number of recipient children. Consequently, the ratio (children with SEN / recipient children) will be very high in these countries sending a wrong message. For this reason, we consider that the total number of disabled children ought to be based on survey estimations.

Consequently, the total number of pupils with SEN (mainstream and special education) could be compared to the total number of disabled children. In this case, we would have to use estimates based on existing surveys as discussed in Part I. Criticism would focus on estimation methods. The measurement of disability among children is a debatable issue particularly with regard to learning, behaviour and communication problems which are difficult to measure for this age group.

An alternative solution is to compare the total number of pupils with SEN (mainstream and special education) to the total number of pupils of the same age. This would avoid critics on the nature of the denominator.

We can estimate the ratio of pupils with SEN (mainstream and special) to the estimated total number of disabled children. We may compare this ratio with the equivalent ratio for all children.

## 3. Pupils attending special schools

The same issues reported in the first chapter of this part apply here.

As noted above, the major problem for an international comparison of data concerns the definition of the target group.





The majority of Member States use the term "Special educational needs" but it covers different categories. Certain countries have added children with social problems while other countries have included minority children (a category that might include immigrant children and travellers). Consequently, these groups ought to be excluded for comparability reasons. Most Member States report categories which enable us to isolate these groups in order to retain only disabled pupils.

Again as noted above, the group of disabled children is not a homogenous group. Information concerning the nature of disability/special education need is important for the formulation of relevant policies. Efforts therefore ought to be devoted to harmonising existing classifications.

The distribution by age group is not relevant here. Special education is not structured as mainstream schools, for example some special curricula are organised over longer school periods.

The study 'Compilation of disability statistical data from the administrative registers of the Member States' (2007) by APPLICA & CESEP & European Centre presents a summary of administrative data in Chapter II. EASNE report the same administrative data used in the Applica study, but this data need much work in order to achieve any comparability.

## Figure 4: Children with SEN in special education as a % of students in compulsory education (primary and lower secondary)<sup>1</sup> (SEN: special educational needs)



<sup>1</sup>: Compulsory education ranges generally from 5/6 to 15/16 years old except in Belgium, Italy and Lithuania where it continues till 18 years. IE: only first level only. \*: Data might include pre-primary level. Source: See text

The alternative could be to indicate children with SEN in special schools as a % of all children with the same level of needs. This could help us to show the proportion of disabled children in mainstream and in special schools.

The sources used in the above-mentioned study include in particular:

- Eurybase, the information database on education systems in Europe,
- EADSNE (European Agency for development of special need in education);
- UNICEF,
- OECD, and
- National Ministries of Education.





Administrative registers enable us to estimate the number of children with SEN in special schools as a % of pupils in compulsory education; We may present this indicator by sex (girls/boys).

It is necessary to harmonise existing administrative classifications concerning the type of disability / special education need.

## 4. Educational attainment at school

EU SILC provides the 'Highest ISCED level attained' (PE040). The following classification is provided (International Standard Classification of Education):

- 0 pre-primary education
- 1 primary education
- 2 lower secondary education
- 3 (upper) secondary education
- 4 post-secondary non tertiary education
- 5 first stage of tertiary education (not leading directly to an advanced research qualification) and second stage of tertiary education (leading to an advanced research qualification)

EU-SILC provides also the age in years for persons aged 16 or more. Consequently, we can measure the highest education level attained at a given age (e.g. 24) for people with and without a limitation.

It is important to note that young people with a limitation and older people with a limitation might share different characteristics. Disability is a life event which is not necessarily congenital or acquired at an early age. A major problem for people who acquired disability at an early age is access to education. On the contrary, persons who acquire a disability at a later age do not have (or did not) have this problem. Probably, they have attended mainstream education and they had in the past an ordinary job. However, it is important to present the educational level of all disabled people in order to assess the link between disability and educational level.

Consequently, it is interesting to present the educational attainment of all people with a disability as well.

We can also use the Labour Force Survey (ad hoc modules 2002 and 2011) to estimate the highest ISCED level attained for working age people with and without disabilities. The information delivered by the LFS survey is complementary to the previous one as it focuses on 'limitations in working activities'.

The EU-SILC survey permits us to estimate the educational attainment of people with and without a disability by ISCED level at a specific age and for all adults. We may compute this indicator for women and men.

The LFS ad hoc modules provide similar information for people with working limitations.





## 5. Early school leavers

There are two ways to estimate the number of early school leavers.

The first method uses administrative data. First, the number of disabled children at ordinary and special schools is ascertained. Then this number is compared with the total number of disabled children. The latter could be the number of children receiving a disability related benefit. National and OECD data provide this information. Once we have the number of disabled children at school and the total number of disabled children, we may estimate early school leavers.

This method presents a major disadvantage. The method (in particular the definition) used to estimate the number of children with SEN and the number of disabled children receiving a disability related benefit is not the same. Furthermore, this method is sensitive to social policy. Countries with a generous social system provide a financial benefit to a large number of disabled children. These countries might tend to have a high estimator of early school leavers. On the contrary countries with a restrictive social protection policy will tend to have a low rate of early school leavers.

The alternative is to use surveys. As we noted, most European and international surveys cover people aged 15 years or more. A limited number of national surveys cover younger children but the data are not comparable across countries.

The EU-SILC survey provides information on "Self-defined current economic status" (PL030). It distinguishes:

- 1 Working full time
- 2 Working part-time
- 3 Unemployed
- 4 Pupil, student, further training, unpaid work experience
- 5 In retirement or in early retirement or has given up business
- 6 Permanently disabled or/and unfit to work
- 7 In compulsory military community or service
- 8 Fulfilling domestic tasks and care responsibilities
- 9 Other inactive person

This permits us to estimate the number of disabled young (e.g. age group: 16-19) pursuing education and those who have left school and compare it with young adults without disability.

The EQLS survey contains a similar question but this survey covers people aged 18 or more.

The EHIS survey asks "How would you define your current labour status"? (HH.8). It distinguishes:

- 1. working for pay or profit (including unpaid work for a family business or holding, including an apprenticeship or paid traineeship, including currently not at work due to maternity, parental, sick leave or holidays)
- 2. unemployed
- 3. pupil, student, further training, unpaid work experience
- 4. in retirement or early retirement or has given up business





- 5. permanently disabled (Including longstanding illness or health problem)
- 6. in compulsory military or community service
- 7. fulfilling domestic tasks
- 8. other. Please specify: \_\_\_\_

The EHIS survey covers generally persons aged 15 and more. Consequently, information ought to be similar as for the EU-SILC survey.

EU-SILC permits us to estimate the number of disabled young people who are at school and those who have left and compare it with non-disabled young people.

## 6. Degree / level qualification compared to general population

The EU-SILC survey provides information on the International Standard Classification of Occupations level (ISCO-88 (COM)) (PL050). This variable refers to the main job (current main job for people at work or last main job for people who do not have a job).

The basis for the classification in the ISCO-88 scheme is the nature of the job itself and the level of skill required. A job is defined as the set of tasks and duties to be performed. Skills are the abilities to carry out the tasks and duties of a job. Skills consist of two dimensions: skill level and domain specialisation. The skill level is related to the level of educational attainment.

The available information is detailed. However, it is sufficient to take the first digit of the International Standard Classification of Occupations (ISCO). This means 10 categories (e.g. 1. Legislators, senior officials and managers; 2.Professionals; 3.Technicians and associate professionals; 4.Clerks; 5.Service workers and shop and market sales workers; 6.Skilled agricultural and fishery workers; 7.Craft and related trades workers; 8.Plant and machine operators and assemblers; 9.Elementary occupations; 10.Armed forces).

It is important to present this indicator for women and men in order to identify any gender discrimination or segregation.

We can also use the Labour Force Survey (ad hoc modules 2002 and 2011) to estimate the level of qualification for working age people with and without disabilities. The information delivered by the LFS survey is complementary to the EU-SILC as it focuses on 'limitations in working activities'.

The EU-SILC survey enables us to estimate the distribution of people with and without a disability by occupational level (both for women and men).

The LFS ad hoc modules provide similar information for people with working limitations.





## 7. Disabled students in higher education

The EU-SILC survey reports 'Current education activity' (PE010). The question stresses whether the person is currently participating in an educational program. The survey specifies ISCED level currently attended (PE020). As before, it uses the International Standard Classification of Education (ISCED):

- 0 pre-primary education
- 1 primary education
- 2 lower secondary education
- 3 (upper) secondary education
- 4 post-secondary non tertiary education
- 5 first stage of tertiary education (not leading directly to an advanced research qualification) and second stage of tertiary education (leading to an advanced research qualification)

Consequently, we may estimate the percentage of persons with and without a disability currently enrolled in tertiary education by gender.

The EU-SILC survey enables us to estimate the percentage of persons at a specified age group with and without a disability currently enrolled in tertiary education by gender.

## 8. Highest level qualification

This is covered in point 6.

We may note that according to the International Labour Office (ILO), occupations that involve the performance of the same tasks should always be classified in the same place in ISCO, even when the formal educational qualifications required or held may differ from one country to another or from one individual to another.

## 9. Participation rate in life-long learning

Lifelong learning includes all learning activity undertaken throughout life, with the aim of improving knowledge, skills and competences, within a personal, civic, social, and employment related perspectives.

As indicated in point 7., EU SILC reports 'Current education activity' (PE010). The question focuses on whether the person is currently participating in an educational program. The survey specifies ISCED level currently attended (PE020). The age of the interviewee is reported as well as limitation. Consequently, we may present the percentage of people with and without a limitation aged 25+ participating in an educational programme.

However, the data are restricted as they cover only formal education. The following adult programmes are not classified as educational activity and consequently are not reported:

- vocational education organized by a firm without leading to an official award or certification
- any non-formal education without leading to an official award or certification.





The Adult Education Survey (AES) is part of the EU Statistics on lifelong learning. The surveys have been carried out by countries in the EU, EFTA and candidate countries between 2005 and 2008. The EU-AES is a pilot exercise which for the first time proposed a common EU framework including a standard questionnaire, tools and quality. It includes notably questions on:

- Participation in formal, non-formal and informal education, and
- Non-participation and obstacles to participation in training

The AES covers persons aged 25-64 and includes a question on 'Participation in Education and Training (1.3.1.Formal education, 1.3.2.Non-formal education)'. However, there is no question on disability. The only group which we can distinguish is permanently disabled (labour status) but this is a very restrictive definition covering disabled people not participating on the labour market (employed and unemployed). This provides some opportunity to overview of the situation of this group and the opportunities for further education but it is important to note that this might include primarily people who are inactive and those with severe limitations.

AES puts another interesting question on 'Obstacles in participation in education'. However, the answer combines age and disability ("Your health or age" is among the obstacles in participating in education).

Given the importance of this survey, it might be interesting to have a question on disability.

The LFS survey has a block of detailed questions covering training and learning activities. However, as we know this survey does not regularly include a question on disability. The LFS 2002 included an Ad hoc module on disability. This provides very detailed information but is relatively old. The next survey with a disability module is expected for 2011 and the first results expected in 2012. According to available information, the only Member States which have introduced a disability question in their annual LFS survey are Slovakia and the UK. From spring 1997 the UK LFS asks all its working age respondents: 'Do you have any health problems or disabilities that you expect will last more than a year?' If they answer yes to this question, they are also asked to say to what kind(s) of health problem or disability(ies) they have, based on a list read to them by the interviewer.

Information provided by the LFS ad hoc modules are complementary to the information provided by the EU-SILC as it focuses on work limitations.

It is interesting to note the questions included in the EDSIM module, notably:

- Do you have access to all the learning opportunities that you want nowadays?
- What limits your access to learning opportunities? (List of barriers).

We may use the EU-SILC survey to estimate the percent of adults with and without limitations participating in formal training.

We may use the LFS ad hoc modules (2002 and planned 2011) to estimate the percentage of disabled (work limitations) and non-disabled people in government training schemes. Introduce disability questions (work limitations) in the annual LFS surveys.





We may use EDSIM to estimate the number who report barriers. We ought to introduce disability questions (MEHM) in the AES survey.

## 10. Participation in government training scheme

The LFS survey presents information on 'Education or training received during previous four weeks' and on 'Learning activities'. It presents the type of instruction, level of training, field of training, field of the most recent taught learning activity, number of hours, purpose, length, etc.

However, as we know this survey does not include a regular question on disability. Only the LFS 2002 included an Ad hoc module on disability and the next survey with a disability module is expected for 2011 and the first results expected in 2012. According to available information, the only Member States which have introduced disability questions in their annual LFS survey are Slovakia and the UK.

The EU-AES survey includes a wide range of questions on:

- (a) Participation in Education and Training
  - a. Formal education
  - b. Non-formal education
- (b) Obstacles in participation in education
- (c) Informal learning
- (d) Access to information about learning possibilities

As the LFS, the EU-AES survey collects information on hours of training, length, level, etc. One interesting question concern: "Who was the provider of this activity"? It distinguishes: 1.Formal education institution; 2.Non formal education and training institutions; 3.Commercial institution where ET is not the main activity (e.g. equipment suppliers); 4.Employer; 5.Employers' organisations, chambers of commerce; 6.Trade unions; 7.Non-profit associations, e.g. cultural society, political party; etc.

Given the fact that some countries favour education and training through public bodies while others through private or public/private bodies, we consider that the criterion 'government training scheme' is not relevant. The important dimensions are whether training and learning activities:

- lead to a formal diploma; or whether
- they are organised in the framework of formal education institutions or by employers, etc.

We may use the LFS ad hoc modules (2002 and planned 2011) to estimate the percentage of disabled and non-disabled people in government training schemes. Introduce disability questions (work limitations) in the annual LFS surveys.

Propose the inclusion of disability questions (MEHM) in the EU-AES survey.





## 11. Transition from school to work (proposed)

For the most part, previous indicators draw on cross-sectional data. Yet questions of change over time are critical to how we understand employment trajectories in relation to individual characteristics, policy change and differences in underlying labour market institutions.

The EU SILC survey enables us to present quantitative data on the transition of young disabled between education/training and the labour market. We can notably present transition indicators by economic status.

# Table 5: Transition indicators concerning education/training and the labour market for young adults:

Type of situation previous year	Type of situation next year	% AT BE DK DE EL FR etc			
	Employee-full time				
Education/Training	Employee-part-time				
	Self-employee				
	Education/training (further)				
	Unemployed				
	Inactive (possibly different				
	types)	100 100 100 100 100			
	Total	100			

This table can be computed for young adults with and without limitations in order to compare their trajectories and identify any path/mechanism leading to exclusion from the labour market.

The EU SILC survey enables us to present longer trajectories but they might be more difficult to explain in a user friendly way at a wide public.

We may use the EU-SILC survey to present quantitative indicators describing the transition between education and the labour market for young adults by sex.

This offers some interesting possibilities, although very time consuming in data analysis<sup>50</sup>.

<sup>&</sup>lt;sup>50</sup> But see also the OECD project on 'Pathways for disabled students to tertiary education and employment', <u>http://www.oecd.org/edu/equity/sen/pathways</u>





#### VI. WORK AND EMPLOYMENT

Article 27 of the UN Convention (Work and employment) is important here. During discussions and consultations a list of indicators were proposed. They refer to persons with disabilities and include (with possible priority indicators shown in italics):

- 1. Proportion of the public in favour of specific measures for equal opportunities in employment
- 2. Disabled people who need/use personal assistance at work
- 3. Disabled people who need/use special equipment at work
- 4. Disabled people who need/use special working arrangements at work
- 5. Employment rate of disabled women and men compared to general population
- 6. Unemployment rate of disabled women and men compared to general population
- 7. Activity rate of disabled women and men compared to general population
- 8. Inactivity rate of disabled women and men compared to general population
- 9. Full-time / part-time work
- 10. Disabled working age people in work who would like to work more hours
- 11. Self-employed / employers
- 12. Senior managers, company directors, professionals
- 13. Type of contract (temporary / permanent) (proposed by the author)
- 14. Disabled people living in jobless households compared to general population
- 15. Long-term unemployment
- 16. Disabled people who have ever had paid work
- 17. Proportion of disabled women and men who are low paid
- 18. Labour market transitions (proposed by the author)

It would be relevant to compare findings from the 2002 and 2011 ad hoc modules of the LFS.

## 1. Proportion of the public in favour of specific measures for equal opportunities in employment

The special Eurobarometer 2006 on 'Discrimination in the European Union: Perceptions, Experiences and Attitudes' (2008) asks: Would you be in favour of or opposed to specific measures being adopted to provide equal opportunities for everyone in the field of employment? Measures such as, for example special training schemes or adapted selection and recruitment processes, for people depending on their...(QA9).

The answer distinguishes: 1.Sexual orientation; 2.Disability; 3.Religion or belief; 4.Age; 5.Gender; 6.Ethnic origin. The ordering is: 1.Totally in favour; 2.Somewhat in favour; 3.Somewhat; 4.opposed; 5.Totally opposed.

The disadvantage of the above survey is that it is not repeated annually.

The International Social Survey Programme (ISSP) covers several European countries<sup>51</sup>. An interesting question asks (Q84): "To what extent do you feel concerned about the living conditions of: 1.Elderly people; 2.Unemployed people; 3.Immigrants; 4.Sick and disabled people; 5.Children in poor families.

<sup>&</sup>lt;sup>51</sup> Austria, Bulgaria, Cyprus, Czech, Denmark, Finland, Belgium (Flanders), France, Germany, Great Britain, Hungary, Ireland, Italy, Latvia, the Netherlands, Northern Ireland, Norway, Poland, Portugal, Slovenia, Spain, Sweden, Switzerland.





The possible answers being: Very much; much; to a certain extent; not so much; not at all.

Although, this information is more general, it completes information provided by the Eurobarometer.

We may estimate the percentage of people being in favour of specific measures ... for disabled.

Also, we may present the percent of people being concerned about the living conditions of 'sick and disabled people' (noting the definitional difficulties of conflating disability with 'sickness', discussed earlier)

#### 2. Disabled people who need / use personal assistance at work

The identification of a need and the subsequent use of personal assistance at work seem to be an important method for the integration of disabled people at work.

The EDSIM will cover 'Lack of personal help or assistance'. Lots of tasks can be performed if people are available to help. This can be physical help, giving instructions, carrying our instructions or giving encouragement. (Code 7);

The EDSIM pilot module asked:

Why are you limited in the type or amount of work that you do?

- (1) Lack of job opportunities
- (2) Family responsibilities
- (3) Lack of qualifications/experience
- (4) A health condition, illness or disease
- (5) Some activity limitation such as difficulty in: seeing, hearing, communicating or concentrating or walking, going up steps, keeping one's balance, reaching, stretching, carrying or gripping.
- (6) Lack of special aids or equipment
- (7) Lack of personal help or assistance
- (8) Employers lack of flexibility
- (9) Affects receipt of benefits or services
- (10) Other reasons

Option (7) provides interesting information. However, this question excludes people who need it and receive it.

The previous question is addressed to people who work. An adapted question covers unemployed people (seeking and not seeking for work).

The LFS 2011 ad hoc module on employment of disabled people includes a question on personal assistance at work: Because of the health problem or difficulty the person needs/uses personal assistance to enable him/her to work (AV9): Yes / No. This question does not distinguish between 'need' and 'use' of personal assistance.

The LFS Ad hoc module on disability 2002 includes the following questions:





- 1. Whether some form of assistance is provided to work (229);
- 2. Whether some form of assistance is needed to work (230).
- 3. Type of assistance provided/needed to work (231):
  - a) Assistance with kind of work
  - b) Assistance with amount of work
  - c) Assistance with mobility to get to and from work
  - d) Assistance with mobility at work
  - e) Support and understanding by superiors and colleagues

SHARE provides information on support in difficult situations at work but it does not specify the type of support. The question (EP031) is "I receive adequate support in difficult situations. (Would you say you strongly agree, agree, disagree or strongly disagree"?

The EDSIM module will enable us to estimate the percent of disabled people who need personal help or assistance at work.

The LFS 2011 ad hoc module will permit us to estimate the percent of disabled people who need or use personal assistance at work.

The LFS ad hoc module 2002 enables us to estimate the percent of disabled people who: - need assistance (Whether some form of assistance is needed to work); and - receive assistance (Whether some form of assistance is provided to work.

## 3. Disabled people who need / use some equipment at work

The EDSIM will cover 'Lack of special aids or equipment'. People with various activity limitations can still work in lots of jobs if the right assistive devices are available (Code 6);

The EDSIM module asks:

Why are you limited in the type or amount of work that you do?

- (1) Lack of job opportunities
- (2) Family responsibilities
- (3) Lack of qualifications/experience
- (4) A health condition, illness or disease
- (5) Some activity limitation such as difficulty in: seeing, hearing, communicating or concentrating or walking, going up steps, keeping one's balance, reaching, stretching, carrying or gripping.
- (6) Lack of special aids or equipment
- (7) Lack of personal help or assistance
- (8) Employers lack of flexibility
- (9) Affects receipt of benefits or services
- (10) Other reasons

Option (6) provides interesting information. However, this question excludes people who need some equipment at work and receive it.


The previous question is addressed to people who work. An adapted question covers unemployed people (seeking and not seeking for work).

The LFS 2011 ad hoc module on employment of disabled people include a question on equipment at work (AV10): "Because of the health problem or difficulty the person needs / uses special equipment or has/needs workplace adaptations to enable him/her to work": Yes / No.

As noted above, the LFS Ad hoc module on disability 2002 includes the following questions:

- 1. Whether some form of assistance is provided to work (229);
- 2. Whether some form of assistance is needed to work (230).
- 3. Type of assistance provided/needed to work (231)

A limited number of special disability surveys treats work adaptation:

- the French survey 'Health, Disability and Work' ('Santé, Handicap et Travail') (2007) includes a question on the need/benefit of work place adaptations;
- the French SIP survey ('Health and career development survey': '*Enquête santé Itinéraire professionnel*') (2006/2007) includes a question on work place adaptation;
- the Spanish 'Impairments and Disabilities' ('*Defficiences & Discapacitades*') (2008) includes the following question: "Because of his disability has made some changes in some of the jobs ... For example, adjustments to the facilities, telephones, computers, ...".

The EDSIM will enables us to estimate the percent of disabled people who need special aids or equipment.

The LFS 2011 enable us to estimate the percent of disabled people who need or benefit special equipment or workplace adaptations.

# 4. Disabled people who need / use special working arrangements at work

The EDSIM will cover 'Employers lack of flexibility over when one can work'. Employers may not allow people flexibility in the hours or days when the employees can work (Code 9).

The EDSIM module asks:

"Why are you limited in the type or amount of work that you do?

- (1) Lack of job opportunities
- (2) Family responsibilities
- (3) Lack of qualifications/experience
- (4) A health condition, illness or disease
- (5) Some activity limitation such as difficulty in: seeing, hearing, communicating or concentrating or walking, going up steps, keeping one's balance, reaching, stretching, carrying or gripping.
- (6) Lack of special aids or equipment
- (7) Lack of personal help or assistance





- (8) Employers lack of flexibility
- (9) Affects receipt of benefits or services
- (10) Other reasons"

Option (8) provides interesting information. However, this question excludes people who need special working arrangements and receive them.

The previous question is addressed to people who work. An adapted question covers unemployed people (seeking and not seeking for work).

The LFS 2011 ad hoc module on employment of disabled people is expected to include the following question (AV8) "Main reason for limitation in work (number of hours, type, getting to and from work) that is not related to longstanding health conditions/diseases or basic activity difficulties:

- 1. Lack of qualifications/experience
- 2. Lack of appropriate job opportunities
- 3. Lack or poor transportation to and from workplace
- 4. Employers' lack of flexibility
- 5. Affects receipt of benefits
- 6. Family/caring responsibilities
- 7. Personal reasons
- 8. Other reason
- 9. No limitation in work
- 10. Not applicable (not included in the filter)".

This question provides a proxy for the need of special working arrangements (see answer 4).

The LFS 2011 ad hoc module on employment of disabled people is expected to include an additional question on special working arrangements (AV11): "Because of the health problem or difficulty the person has /needs special working arrangements to enable him/her to work (such as sedentary jobs, teleworking, flexible hours or less strenuous work); Yes / No.

As noted above, the LFS Ad hoc module on disability 2002 includes the following questions:

- 1. Whether some form of assistance is provided to work (229);
- 2. Whether some form of assistance is needed to work (230).
- 3. Type of assistance provided/needed to work (231)

Concerning special disability surveys, we have identified only the French SIP survey treating work-time adaptations and mobility assistance (from home to work and inside the working place) ('*Enquête santé – Itinéraire professionnel*': 'Health and career development'; 2006/2007).

The EDSIM enables us to estimate the percent of disabled people who need special working arrangements.

The LFS 2011 will enable us to estimate:

- the percent of disabled people who need special working arrangements;
- the percent of disabled people who need or benefit special working arrangements.





- 5. Employment rate of disabled women and men compared to general population
- 6. Unemployment rate of disabled women and men compared to general population
- 7. Activity rate of disabled women and men compared to general population
- 8. Inactivity rate of disabled women and men compared to general population

#### 9. Full-time / part-time work

The EU-SILC survey presents the 'Self-defined current economic status' (PL030):

- 1 Working full time
- 2 Working part-time
- 3 Unemployed
- 4 Pupil, student, further training, unpaid work experience
- 5 In retirement or in early retirement or has given up business
- 6 Permanently disabled or/and unfit to work
- 7 In compulsory military community or service
- 8 Fulfilling domestic tasks and care responsibilities
- 9 Other inactive person

This information enables us to estimate the employment rate, the unemployment rate, the activity rate, the inactivity rate and part-time / full-time of people with and without limitations by gender living in private households.

There are several surveys which provide similar information, notably:

- The European Social Survey (ESS);
- The European Quality of Life Survey (EQLS);
- The European Health Interview Survey (EHIS);
- Several national surveys.

However, the EU-SILC survey provides the most relevant data from a statistical point of view (comparability across countries, size of sampling, etc.).

The LFS 2002 ad hoc module on disability presents work limitations (health problem restricts kind of work that can be done; amount of work; mobility to and from work). The LFS 2011 ad hoc module on employment of disabled people is expected to focus also on work disability (number of hours that he/she can work; type of work (for instance, having problems in carrying heavy loads, working outdoors, sitting for a long time); getting to and from work).

Information provided by the LFS ad hoc modules are complementary to the EU-SILC survey as these two surveys use different definitions of disability.

A limited number of national surveys present 'work limitations'. The standard question with some variations is: "Do you have any health problems or disabilities which limit the amount or type of work you can do"? We may cite the following surveys:





- The French survey 'Health Disability and Work' ('Santé, Handicap et Travail') (2007),
- The British Household Panel Survey (2007),
- The Spanish 'Survey on Disability, Personal Autonomy and Situations of Dependency' ('Encuesta de Discapacidad, Autonomía personal y situaciones de Dependencia') (2008).

It is desirable to report both definitions (limitations on daily activities and work limitations) since they provide different information which might be useful during the elaboration of employment policies.

Available surveys (notably EU-SILC) provide sufficient information for the estimation of the percent of people with and without 'limitations' (by gender) in:

- Employment (limited in daily activities and work limitations),
- Unemployment (limited in daily activities),
- Activity (limited in daily activities and work limitations),
- Inactivity (limited in daily activities),
- Part-time / Full time (limited in daily activities and work limitations).

The LFS ad hoc modules provide similar information on 'limitations' in the amount or type of work people can do.

#### 10. Working age people in work who would like to work more hours

The EU-SILC survey presents the 'Reason for working less than 30 hours' (PL120). It distinguishes:

- 1 Undergoing education or training
- 2 Personal illness or disability
- 3 Want to work more hours but cannot find a job(s) or work(s) of more hours
- 4 Do not want to work more hours
- 5 Number of hours in all job(s) are considered as a full-time job
- 6 Housework, looking after children or other persons
- 7 Other reasons

Consequently, we may estimate the percent of disabled people who work less than 30 hours and want to work more hours but cannot find a job(s) or work(s) of more hours. This indicator can be presented by gender. Age is also an important dimension.

The LFS presents a similar question as EU-SILC but includes two additional questions:

- Wish to work usually more than the current number of hours (55), and
- Number of hours that the person would like to work in total (56/57).

Consequently, the Ad hoc module 2002 on disability enable us to estimate the percent of working disabled people who 'Wish to work usually more than the current number of hours' by gender and age.

The next Ad hoc module on employment of disabled people is expected for 2011.





The Ad hoc module 2002 on disability enables us to estimate the percent of working disabled people who 'Wish to work usually more than the current number of hours' by gender and age. The next collection is planned for 2011.

The EU-SILC enable us to estimate the percent of disabled people who work less than 30 hours and want to work more hours but cannot find a job(s) or work(s) for more hours, by gender and age.

# 11. Self-employed / employers

EU SILC provides information on 'Status in employment' (PL040) and distinguishes:

- 1. self-employed with employees
- 2. self-employed without employees
- 3. employee
- 4. family worker

Consequently, we can estimate the number of people with and without limitations being self-employed or employers. This information can be presented by gender, age, etc.

Similarly, the LFS presents 'Professional status' (26) and distinguishes the same categories as EU SILC. The Ad hoc modules of 2002 and the expected for 2011 provide similar information for people with limitations at work.

The EU-SILC survey permits an estimate of people with and without 'limitations' who are selfemployed or employers by gender.

The LFS ad hoc modules provide similar information for people with limitations at work.

# 12. Senior managers, company directors, professionals

The EU-SILC presents whether the worker has a 'Managerial position' and distinguishes supervisory and non-supervisory position.

As noted above, EU-SILC provides a detailed (two digits) classification of 'Occupation (ISCO-88 (COM))' (PL050). The first digit of the International Standard Classification of Occupations (ISCO) presents the following 10 categories (e.g. 1. Legislators, senior officials and managers; 2.Professionals; 3.Technicians and associate professionals; 4.Clerks; 5.Service workers and shop and market sales workers; 6.Skilled agricultural and fishery workers; 7.Craft and related trades workers; 8.Plant and machine operators and assemblers; 9.Elementary occupations; 10.Armed forces).

The two digits classification enables us to present the percent of people with and without limitations by gender for the following occupations:





# 1. Legislators, senior officials and managers

- 11 Legislators, senior officials and managers
- 12 Corporate managers
- 13 Managers of small enterprises

#### 2. Professionals

- 21 Physical, mathematical and engineering science professionals
- 22 Life science and health professionals
- 23 Teaching professionals
- 24 Other professionals

The LFS presents 'Occupation' (30/33) and is coded at a very detailed way (3 digits). Available data cover 2002 and the next will be collected in 2011.

The EU-SILC survey enables us to estimate the percent of people with and without limitations by gender for by ISCO at two digits level.

The LFS ad hoc modules provide similar information for people with limitations at work.

#### 13. Type of contract (proposed)

The type of contract is an important dimension for the study of unstable employment and marginalisation on the labour market. In a context of flexicurity policies, it is important to know whether people with disabilities hold temporary or permanent jobs.

EU SILC presents the 'Type of contract' (PL140) and distinguishes:

- 1. Permanent job/work (contract of unlimited duration)
- 2. Temporary job/work (contract of limited duration)

The LFS survey presents similar information. Available data cover 2002 and the next survey is expected for 2011.

We may use EU-SILC to estimate the percent of people with and without limitation with a temporary job; We may estimate this indicator by gender.

The LFS ad hoc modules provide similar information for people with limitations at work.

# 14. Disabled people living in jobless households compared to general population

EU SILC includes two blocs of information; the household and the personal file. The personal file includes information on limitations. By combining the two files, we can estimate the number of disabled people living in jobless households compared to general population.

In addition, the EQLS has a household grid and enables a similar estimate. However, EU-SILC data are collected more regularly and statistically better (size of the sample).





The EU-SILC survey provides information enabling us to estimate the number of disabled people living in jobless households and compare to all households (or households without disabled people).

# 15. Long-term unemployment

EU SILC presents the 'Number of months spent in unemployment in income reference period' (PL080). The value ranges from 1 to 12, given that those indicating 12 comprise all those with 12 or more months in unemployment.

LFS presents in months the 'Duration of search for employment' (83). Available data cover 2002 and the next LFS ad hoc module on employment of disabled people is expected for 2011.

Finally, the EQLS has an explicit question on 'unemployed 12 months or more'.

EU SILC enables us to estimate the percent of long-term unemployed (12 months or more) of non-people. The indicator can be constructed by gender and age.

The LFS ad hoc modules provide similar information for people reporting 'limitations' at work.

# 16. Disabled people who have ever had paid work

EU SILC presents whether 'Person has ever worked' (PL015). The answer is Yes, No.

Vacations jobs undertaken by students, from which they return to studies or to other nonwork situation and any other casual work undertaken from time to time are disregarded. Normally, having ever worked refers to persons who worked on full or partial time basis for at least 6 months.

The EHIS survey asks: "Have you ever worked for pay or profit"? (HH.9). The answer is Yes/No.

The LFS survey presents 'Previous work experience of persons not in employment'. A question asks whether the person has 'Existence of previous employment experience' (66). The answer distinguishes:

- 1. Person has never been in employment (purely occasional work, such as vacation work, compulsory military or community service are not to be considered as employment)
- 2. Person has already been in employment (purely occasional work, such as vacation work, compulsory military or community service are not to be considered as employment

Available data cover 2002 and the next LFS ad hoc module on employment of disabled people is expected for 2011.





Finally, the EQLS asks (Q1) 'Have you ever had a paid job'? Given the statistical advantages of EU SILC, notably its size and periodicity, the relevant indicator ought to use EU SILC data.

The EU-SILC survey enables us to estimate the percent of people with and without limitation who have ever worked. The indicator can be calculated by gender and/or age.

The LFS ad hoc modules provide similar information for people with limitations at work.

# 17. Proportion of disabled women and men who are low paid

EU SILC reports 'Employee income'. Employee income is defined as the total remuneration, in cash or in kind, payable by an employer to an employee in return for work done by the latter during the income reference period.

The employee income is broken down into:

- 1. Gross employee cash or near cash income (PY010G)
- 2. Gross non-cash employee income (PY020G)
- 3. Employers' social insurance contributions (PY030G)

Some countries report 'Net employee cash or near cash income' (PY010N). The net income component corresponds to the gross income components but the tax at source, the social insurance contributions or both are deducted.

On the other hand, EU SILC presents the 'Number of hours usually worked per week in main job, second, third, etc.) (PL060 and PL100).

These data enable us to estimate the hourly gross employee wage for people with and without a disability. Also, we can estimate means or medians of hourly gross employee wage for each group.

The EU-SILC also presents 'gross monthly earnings for employees' (PY200G). It refers to the monthly amount received in an employee's main job.

The EU-SILC survey enables us to estimate the proportion of disabled women and men who are low paid.

# **18.** Labour market transitions (proposed)

Since the introduction of EU's job quality concept, the EU monitors transitions by employment statuses, type of labour contract and pay level. The recent Communication on flexicurity also strengthens the need to monitor transitions over the lifecycle on both the flexibility and security dimensions of work, because flexicurity reforms shifted the focus from protecting the job to supporting workers' transitions throughout their working lives. Given the growing need to both facilitate and support transitions, it is important to monitor these transitions timely and accurately in order to strengthen the evidence base for policy making.





The EU-SILC survey provides all necessary information to establish the existence of transitions. As an example, transitions by employment statuses can be calculated either based on the Self-Defined Current Economic Status (PL 30) or computed on the basis of the Most Recent Change in the Individual's Activity Status (PL180). The calendar of activities (PL210) may also allow calculating intra-annual transitions by employment statuses.

#### Table 6: Transitions on the labour market

Situation previous year	Situation next year	%				
		AT	BE D	K DE	EL F	R
		etc				
	Employed					
Employee	Education/training					
	Non-employed					
	Total	100	100	100	100	100
		100				
Education/training	Employed					
	Education/training					
	Non-employed					
	Total	100	100	100	100	100
		100				
	Employed					
Non-employed	Education/training					
	Non-employed					
	Total	100	100	100	100	100
		100				

This table could be drawn for example for:

- people with disabilities (limited in the first year); and
- people without disabilities (not limited in both years)

An alternative method could be to count specific patterns of transition that lead to unstable employment and inactivity. We could enlarge the time period and take into account a horizon of three years. In this case, we could for example count the number of people going from precarious employment (part-time, temporary, or low-wage employment) (year 1) to unemployment (year 2) and finally to inactivity (year 3).

The EU SILC enables us to estimate the number of transitions for people with and without a limitation.

We may elaborate dynamic indicators providing information on patterns leading to unstable employment and inactivity using EU-SILC data.





# VII. INCOMES AND POVERTY

Article 28 of the UN Convention (Adequate standard of living and social protection) is important here but also, for example, elements of Articles 26 (Habilitation and rehabilitation).

During discussions and consultations a list of indicators was proposed. They focus on people with disabilities and include the following items (with possible priority indicators shown in italics):

- 1. Households living in relative poverty by gender and age
- 2. Household income (with/without one or more disabled members)
- 3. Household savings/debt
- 4. Risk/rate of poverty (before/after social transfers)
- 5. Sources of household income (e.g. wages, state benefits,...)
- 6. Satisfaction with standard of housing (accommodation meets needs?)
- 7. Disabled people living in inadequate housing
- 8. Housing tenure (e.g. public/private rented, owner occupation)
- 9. Expenditure on disability-related cash benefits

#### 1. Households living in relative poverty by gender and age

The EU-SILC survey presents in the Household file:

- Equivalised disposable income (Total household income (gross and disposable)) (HX090); and,
- Poverty indicator (HX080).

The EU-SILC survey considers that the household is at risk of poverty if the equivalised disposable income is less than 60% of median equivalised disposable income. Eurostat uses this criterion for the estimation of poverty risk.

In order to classify by gender and age group, we have to choose one person inside the household which will be used as the reference for gender and age. For example, we may choose one of the household partners. In this case, we can present the data by age group for the chosen criterion. EU SILC covers people aged 16 years or more. Consequently, we may construct three broad groups, for example: young adults (16-24), working age people (25-64) and older people (65+).

SHARE presents also total income after tax received by all household members in an average month in previous year (HH017). It presents also detailed information on the different types of income. This enables us to estimate the median income and then measure the risk of poverty for different groups. As noted above SHARE covers people aged 50 years or more.

Finally, EQLS enables us to measure equivalised net household income and consequently the risk of poverty for different groups. The question is "If you add up the income from all sources for all the members of the household, do you know what your household's total net monthly income is, that is, the amount that is left over after taxes have been deducted (Q66)"? The question has the advantage of clarity but the survey provides little additional information in order to check its validity.





The EU-SILC survey provides annually equivalised disposable income and risk of poverty for households. We may compute it for households with and without disabled members.

#### 2. Household income (with/without one or more disabled members)

The EU-SILC survey provides information concerning household income. The data enable us to classify households into:

- Households with one or more disabled members; and
- Households without disabled members.

This enables us to estimate income for households with and without disabled members. Furthermore, we may estimate the distribution of households around median income; for example we may compute the percent of households with disabled members below the median income and the percent of households without disabled members below the median income.

SHARE presents also total income after tax received by all household members in an average month in previous year (HH017). It presents also detailed information on the different types of income. This enables us to estimate the median income and then estimate the distribution of people with and without disabilities around the median income. However, as noted above SHARE covers only people aged 50 years or more.

Finally, EQLS enables us to measure equivalised household income and consequently income level and distribution for different groups. However, for statistical reasons (sample size, periodicity, comparability across countries, etc.) it is preferable to use the EU SILC results.

The EU-SILC survey enables us to estimate household income. We may compute this indicator for households with and without disabled members.

#### 3. Household savings / debt

The EU-SILC survey provides information on:

Property income:

1)Property income and 2)Imputed rent (for owners)

- Debts:

1)Financial burden of the repayment of debts from hire purchases or loans and 2)Rent or mortgage

However, the question concerning the financial burden does not present a value but a subjective assessment of whether the repayment is a heavy burden or not (HS150). Consequently, we may construct value indicators concerning mortgage but not for financial debts.





Property income is defined as the income received less expenses occurring during the income reference period by the owner of a financial asset or a tangible non-produced asset (land) in return for providing funds to, or putting the tangible non-produced asset at the disposal of, another institutional unit. The property income is broken down into:

- (1) Interest, dividends, profits from capital investment in an unincorporated business (HY090G)/ (HY090N);
- (2) Income from rental of a property or land (HY040G)/ (HY040N)

We may divide property income by the relevant actualisation rates (rates of interest) and estimate the value of wealth. A more detailed method would be to exploit the longitudinal nature of the survey and take into account past history of property income. However, since we may not estimate the value of debts, this can be an indicator of gross wealth. This indicator could be corrected for mortgages but not for financial debt.

We can hence estimate the gross wealth indicator for households with and without disabled people.

SHARE asks "How much do you and your husband/wife/partner currently have ...)?

- Amount bank account (AS003) (in bank accounts, transaction accounts, saving accounts or postal accounts);
- Amount in bonds (AS007) (in government or corporate bonds);
- Amount in stocks (AS011) (in stocks or shares (listed or unlisted on stock market);
- Amount in mutual funds (AS017);
- Amount individual retirement accounts (AS021);
- Amount contractual saving (AS027);
- Face value life policies (AS030);
- Amount selling own firm (AS042) (If you sold this firm, company or business and then paid off any debts on it, about how much money would be left);
- Amount selling cars (AS051).

This gives the total amount of gross financial and physical wealth.

On the other hand SHARE asks "How much do you and your husband/wife/partner owe in total (AS055). The answer is an amount indicating the total amount for both partners.

Also, this survey asks "How much do all other adults aged 18 and over (except you/and your partner) that live with you have in total savings and investments, after you subtract all the debts they may have? (AS069). This gives the total net amount for all other adults except partners. As a result, we can estimate for the household:

- the ratio: wealth (financial and physical) to debt; and
- the net amount of total wealth (financial and physical assets minus debts).

The above values involve a great amount of uncertainty and risk. Consequently, it is important to use different sources in order to assess any discrepancies in overall indicators.





The two surveys (EU SILC and SHARE) are European surveys and efforts have been deployed to ensure a minimum of comparability across countries. Consequently, we consider that national surveys are of little interest here (e.g. the British 'Household Assets Survey').

The EU-SILC survey permits us to estimate a gross wealth indicator for households with and without disabled people.

SHARE provides information for an estimation of the ratio wealth/debt (for households) but covers only people 50+.

# 4. Risk/rate of poverty (before/after social transfers)

EU SILC presents:

- Total disposable household income (HY020);
- Total disposable household income before social transfers (HY022 and HY023).

Total disposable household income before social transfers including old-age and survivor' benefits (HY023) is defined as: The total disposable income (HY020) minus total net transfers (unemployment benefits (PY090N); old-age benefits (PY100N); survivor' benefits (PY110N); sickness benefits (PY120N); disability benefits (PY130N); education-related allowances (PY140N); family/children related allowances (HY050N); social exclusion not elsewhere classified (HY060N) and housing allowances (HY070N).

This enables us to estimate median income and to estimate the risk of poverty.

SHARE provides also information on different types of income and transfers but does not compute a synthetic indicator as is done by the EU-SILC survey.

The EDSIM asks "What is your household's total net income per month? (IN.3). In addition, it asks "Perhaps you can provide the approximate range instead. Would you tell me which group represents your household's total net monthly income from all these sources after deductions for income tax, National Insurance etc? Is it between x and y decile? (IN.4). The values of the show-card describing the deciles are taken from EU-SILC survey.

The EU-SILC survey provides information enabling us to estimate the risk/rate of poverty before and after social transfers in households with and without disabled members.

# 5. Sources of household income

As noted above, the EU-SILC survey provides information on:

- gross employee cash or near cash income (PY010G);
- gross non-cash employee income (PY020G);
- gross cash benefits or losses from self-employment (including royalties) (PY050G);
- value of goods produced for own consumption (PY070G);





- unemployment benefits (PY090N);
- old-age benefits (PY100N);
- survivor' benefits (PY110N);
- sickness benefits (PY120N);
- disability benefits (PY130N);
- education-related allowances (PY140N);
- family/children related allowances (HY050N);
- social exclusion not elsewhere classified (HY060N);
- housing allowances (HY070N);
- etc.

SHARE provides similar detailed information but as noted, this survey covers people aged 50 years or more.

The EU-SILC provides detailed information on the different sources of household income (including the possibility to distinguish households with and without persons with disabilities).

#### 6. Satisfaction with standard of housing (accommodation meets needs?)

The EQLS survey has a general question (Question 40.4) asking "Could you please tell me on a scale of 1 to 10 how satisfied you are with your accommodation, where 1 means you are very dissatisfied and 10 means you are very satisfied (average)?

The EQLS survey provides an overall satisfaction indicator for people with and without disabilities.

#### 7. Disabled people living in inadequate housing

EU SILC presents a number of indicators, in particular:

- 1. Number of rooms available to the household (HH030);
- 2. Leaking roof, damp walls, rot, etc. (HH040);
- 3. Bath or shower in dwelling (HH080);
- 4. Indoor flushing toilet for sole use of household (HH090).

This enables us to present differences between households with and without disabled persons.

The EQLS asks: "Do you have any of the following problems with your accommodation"? (Q17): Yes/No:

- 1. Shortage of space
- 2. Rot in windows, doors or floors
- 3. Damp or leaks in walls or roof
- 4. Lack of indoor flushing toilet





- 5. Lack of bath or shower
- 6. Lack of place to sit outside

This enables us to present differences between dwelling of people with and without disabilities.

However, these surveys do not include a question on accessibility.

SHARE presents a similar list of accommodation characteristics. Also, a certain number of national surveys containing a disability question include information relative to accommodation, in particular:

- The French 'Health and Social Protection Survey' ('ESPS: Enquête Santé Protection Sociale') (2008);
- 'British Household Panel Survey' (2007).

The EU-SILC and EQLS enable us to construct several indicators concerning the quality of accommodation (space, damp/rot/leaks and toilet/bath/shower) for people with and without disability.

#### 8. Housing tenure (e.g. public/private rented, owner occupation)

The EU-SILC survey defines the 'Tenure status' (HH020) of a household and distinguishes:

- 1. Owner
- 2. Tenant or subtenant paying rent at prevailing or market rate
- 3. Accommodation is rented at a reduced rate (lower price that the market price)
- 4. Accommodation is provided free

The EQLS survey asks the interviewed "Which of the following best describes your accommodation"? (Q16) and distinguishes:

- 1. Own without mortgage (i.e. without any loans)
- 2. Own with mortgage
- 3. Tenant, paying rent to private landlord
- 4. Tenant, paying rent in social/voluntary/municipal housing
- 5. Accommodation is provided rent free
- 6. Other

SHARE has a similar question and the Time Use Survey (2009/2010) has a question on Ownership of the dwelling.

EU-SILC provides information on tenure status for households with and without disabled members.





# 9. Expenditure on disability-related cash benefits

Eurostat data base (ESSPROS: European System of integrated Social Protection Statistics) presents Social benefits by function.

The 'disability' function covers: Income maintenance and support in cash or in kind (except health care) in connection with the inability of physically or mentally disabled people to engage in economic and social activities.

The Disability function includes notably: (periodic/lump sum) cash benefits, periodic care allowance, disability pension, early retirement, accommodation, home help, rehabilitation, etc<sup>52</sup>.

The Eurostat database presents a detailed breakdown of social benefits for the function: Disability:

#### 1. Non Means-tested

# 1.1 Cash benefits

Periodic

Disability pension Early retirement benefit due to reduced capacity to work Care allowance Economic integration of the handicapped Other cash periodic benefits **Lump sum** Care allowance Economic integration of the handicapped Other cash periodic benefits

# 1.2 Benefits in kind

Accommodation Assistance in carrying out daily tasks Rehabilitation Other benefits in kind

#### 2. Means-tested

Cash benefits Benefits in kind

The data are presented as follows:

- 1. Euro per inhabitant (at constant 2000 prices)
- 2. Millions of euro (from 1.1.1999)
- 3. Millions of national currency (including 'euro fixed' series for euro area countries)
- 4. Millions of PPS (Purchasing Power Standard)
- 5. Percentage of GDP
- 6. Purchasing Power Standard per inhabitant

52

http://epp.eurostat.ec.europa.eu/portal/page/portal/living\_conditions\_and\_social\_protection/data/d atabase





Given the big variety of policies and instruments used in the Member States, it is preferable to use total expenditure (No means tested and means tested) as well as cash benefits and benefits in kind.

In fact, if we retain only cash benefits, we will bias comparison between Member States as some might provide care allowances (cash) while others free local services (benefits in kind) for the same goal.

# Figure 5: Invalidity (All schemes; Non means-tested benefits and Means-tested benefits) in % of GDP, 2006



Source: Eurostat

# Figure 6: Invalidity (All schemes; Non means-tested benefits and Means-tested benefits), 2006



# Euro per inhabitant (at constant 2000 prices)

#### Source: Eurostat

The OECD Social Expenditure Database groups benefits with a social purpose in 9 policy areas (SOCX). These areas are as follows: Old age, Survivors, Incapacity-related benefits, Health, Family, Active labour market programmes, Unemployment, Housing, and Other social policy areas. This information is presented in terms of gross domestic product, gross national income, total government expenditure, and in purchasing power parities per head.





The SOCX is broadly compatible with Eurostat's European System of Social Protection Statistics – ESSPROS (Eurostat, 1996).

However, in terms of social domain, the OECD's database has a largest scope as it has developed a methodology, which facilitates the comprehensive accounting of fiscal measures that affect social protection.

Functional categorisations in ESSPROS (Eurostat, 1996) are slightly different. ESSPROS groups items in 7 functions, while SOCX has 9 social policy areas at present.

Incapacity-related benefits listed by SOCX include care services, disability benefits, benefits accruing from occupational injury and accident legislation, employee sickness payments. Incapacity-related benefits include:

# 1. Cash benefits

Disability pensions Pensions (occupational injury and disease) Paid sick leave (occupational injury and disease) Paid sick leave (other sickness daily allowances) Other cash benefits

#### 2. Benefits in kind

Residential care / Home-help services Rehabilitation services Other benefits in kind

Finally, we may note the ILO's Social Security Inquiry (SSI).

Eurostat provides total and detailed disability related expenditure in % of GDP and per capita.





#### VIII. CONCLUSIONS

In the past, surveys centring on people with disabilities were aiming principally to estimate the number of disabled people. This demographic approach was focussing on disability itself. Contextual factors were not taken into account (e.g. accessible buildings, transport and workspaces adaptations, etc.). This trend has changed. Recent surveys focus on the relation between disability and societal and environmental barriers (e.g. EDSIM). The latter surveys enable us to identify barriers in social and economic participation.

In order to improve comparability across thematic and national surveys, it might be interesting to add the standard question on 'Limitation in activities people usually do because of health problems or a disability' into a wide range of thematic surveys. However, even in the case of a simple definition, a certain number of precisions ought to be brought. For example, recent surveys have a forward looking approach by retaining limitations 'expected to last' for a certain period of time and avoid a backward looking approach (last six months).

To this basic reference definition, surveys might add other dimensions. For example, a study on employment issues might require a definition of disability based on work limitations while an analysis of care might require a definition based on activities of daily living (ADLs).

In the short term, the Minimum European Health Module (MEHM) could be inserted in different national and European thematic surveys. This could provide a common reference base for comparison of disability prevalence across Member States as well as across thematic surveys.

In the medium term, we might employ different definitions of disability according to the goal pursued by the survey and incorporate questions on the interaction between disability and social/physical environment. The UN Convention could be the reference framework.

In accordance with the preceding, we consider that a disability question ought to be inserted in the next round of the following surveys:

- Adult Education Survey (AES),
- Labour Force Survey (annual LFS),
- Information and Communication Technologies (ICT survey),
- European Victimisation Survey (EVS) focussing on violence and victims,
- Special surveys focussing on an ageing society,
- National Travel/Mobility Surveys (NTS),
- European Elections Survey (EES).

For a certain number of services, existing surveys ought to make a clear distinction between needs, services used and any gap reported by people with disabilities. The existence of a service does not imply necessarily that it meets / satisfies current demands and aspirations. We need to evaluate any potential gap between aspirations and realisations. This disaggregation of needs and effective use could be inserted notably in the following two surveys:





- European Health Interview Survey (EHIS) as regards care and assistance for ADLs and IADLs, and
- LFS ad hoc modules as regards technical aids and work adaptations.

In assessing needs (demand) and provision of services (supply), we ought to take into account the specificities of certain groups. People with disabilities are not a homogenous group. For example, mobility barriers might prevent people with learning difficulties to access public transport and to travel independently. These barriers ought to be taken into account in elaborating the questionnaires. Current surveys focus exclusively on people with physical mobility restrictions.

The prevalence of disability among children requires different methodologies and sampling techniques. Consequently, instead of adding special modules on current surveys, it might be more efficient to focus on the harmonisation of definitions based on Special Educational Needs (SEN). The current synergy between Eurostat, OECD and Unicef ought to promote the harmonisation of education statistics.

Another problem relates to disabled persons in establishments. Surveys covering people in establishments have specific methodologies and could not easily be inserted into surveys covering private households. An initiative here might consist in promoting the harmonisation of existing national surveys and improving the collection of administrative data.

The insertion of questions on type of disability into surveys is a long-term objective. These questions are useful since people with disabilities are not a homogenous group. The type of limitation is important in analysing potential barriers and specific abilities, and it could be used to help the design of technical aids, adaptations and personal assistance. This harmonisation would require a significant effort in the Member States and might be slowed by two problems: first, the use of different classifications across Member States and second, the need to harmonise classifications used by surveys and those used by administrative registers. This double harmonisation might be a long-term goal.

Proposed indicators are mainly static in nature. They use mainly cross-sectional data and do not make use of longitudinal surveys to cover dynamic aspects, for example:

- Transition from school to work,
- Deteriorating and Improving disability status,
- Channels to marginalisation and precariousness.

A certain number of available surveys (e.g. EU-SILC) enable us to adopt a longitudinal and life-cycle approach.

Furthermore, our social security systems (disability pensions, income support, care allowances, etc.) and employment policies (beneficiaries of active labour market policies, employment quotas, sheltered employment) use extensively administrative registers. These policies constitute a pillar of European and national policies in favour of people with disabilities. We consider that we have to avoid the emergence of two separate blocks of indicators without bridges between them. The 'recognition' of disability by administrative bodies reported by several surveys might constitute a link between the two sources of data (surveys and registers).





05

Several surveys have collected information which seems to be underutilised due to lack of awareness (on the content of certain surveys) and problems related to data accessibility (e.g. because the relevant part of the data is not published, the dataset is not publicly available, or it is difficult to disaggregate).

Future efforts ought to be combined with a policy of better publicity and easier access to microdata (in particular, researchers could make extensive use of more complex analysis techniques if it was possible to work with the microdata from European surveys such as EU-SILC). Existing technologies enable the interested researcher or policy maker to use microdata (draw tables, run regressions, etc.) without necessarily taking possession of a copy of the database. In this direction, some organisations have developed a policy of free and open access, for example some survey microdata are available through internet (e.g. WHO: World Health Survey Data; WVS: World Values Survey). The organisation of surveys is a costly initiative. The investment could be better valorised through a better diffusion of information and data accessibility without transgressing confidentiality rules.





# Abbreviations

Abbreviation	Title	Year	<b>Country/Organisation</b>		
/ Translation					
European / International surveys					
AFS	Adult Education Survey		Furostat		
//LO		2005/2008			
CSES	Comparative Study of Electoral	2001/2005	Center for Political		
	Systems		Studies (USA)		
EB	Eurobarometer on Discrimination in	2008	Eurostat		
FDSIM	Furopean Disability Social	2008	Furostat		
LOSIN	Integration Module	2000	Ediostat		
EES	European Election Survey	2009	University of Mannheim		
EHIS	European Health Interview	2007/2008	Eurostat		
EOLS	European Quality of Life Survey	2007	European Foundation		
			for the Improvement of		
			Living and Working		
			Conditions		
ESS	European Social Survey	2008	European Social Survey		
ESSPROS	European System of integrated	2008	Eurostat		
	Social Protection Statistics				
ESWT	Establishment Survey on Working	2008	European Foundation		
	Time and Work-Life Balance		for the Improvement of		
			Living and Working		
			Conditions		
EU-ICS	EU International Crime Survey	2004/2005	Gallup Europe.		
	(International Crime Victim Survey				
	(ICVS))		<b>F</b>		
EU-SILC	Survey on Income and Living	2008	Eurostat		
	Conditions	2005/00			
EVS	European values study	2005/08	Foundation		
EVS	European Victimisation Survey	2009	Eurostat (Pilot status)		
EWCS	European Working Conditions	2005	European Foundation		
	Survey		for the Improvement of		
			Living and Working		
			Conditions		
ICT	Survey on Information and	2008	Eurostat		
	Communications Technologies				
ICVS	International Crime Victim Survey	2004/2005	Tilburg University (NL)		
ISSP	International Social Survey	2007	ISSP		
	Programme				



LFS	Labour Force Survey ad hoc		Eurostat
-	modules:	2011	
	2011 employment of disabled	2002	
	people		
	2002 disability		
MeAC	Measuring Progress of eAccessibility in Europe (MeAC)	2008	European Commission
OECD	Organisation for Economic Co-	2008	OECD
	operation and Development		
SHARE	Survey of Health, Ageing and	2008/2009	Mannheim Research
	Retirement		Institute for the
			Economics of Aging
			(MEA) (DE)
SOCX	Social Expenditure Database	2008	OECD
TransMONEE	TransMONEE Database	2008	Unicef
TUS	Time use survey	2009/2010	Eurostat
UITP	Accessible public transport	2002	UITP International
			Association of Public
			Transport





Abbreviation	Title	Year	<b>Country/Organisation</b>
/ Translation			

National surveys			
NTS	National Travel Surveys	2006	National Ministries of Transport
Microcensus Survey on Disabled	Personen mit körperlichen Beeinträchtigungen	1995	Austria
Enquête 55+	Enquête sur la mobilité après 55 ans en Wallonie	2001	Belgium
MOBEL	Enquête nationale sur la mobilité des ménages	1999	Belgium
GSOEP Microcensus	German Socio-Economic Panel Household survey Microcensus	2008 2003	Germany Germany
Survey on Disabilities, Personal Autonomy and Dependency	Encuesta sobre Discapacidades, Autonomía personal y situaciones de Dependencia	2008	Spain
ANPAS	Abus et négligence chez les personnes âgées tels que perçu par les intervenants dans des services à domicile	2001	France
FEHAP	Enquête bientraitance / maltraitance FEHAP	2007	France
French Disability survey	Survey on handicaps, disabilities and dependence (enquête Handicap- incapacités-dépendance).	1998/1999	France
HS	Handicap Santé (includes several specific surveys)	2008/2009	France
Health and Care Interview Survey	Enquête nationale sur la santé et les soins médicaux	2002/2003	France
SHT	Health, Disability and Work (Santé, Handicap et Travail)	2007	France
SIP	Health and career development (Enquête Santé-Itinéraire Professionnel)	2006/2007	France
SUMER	Medical monitoring of professional risks Surveillance médicale des risques professionnels.	2009	France
LASA	Longitudinal Aging Study Amsterdam	2005/2006	Netherlands





POLS	Permanent Quality of Life Survey	2003/2004	Netherlands
НСН	Health Care in Households	2003	Poland
NSIDH	National Survey on Impairments, Disability and Handicaps	1995	Portugal
BHPS	British Household Panel Survey	2007	UK
GHS	General Household Survey	2008	UK
HSE	Health Survey for England	2000	UK
MORI	Attitudes of disabled people to community	2002	UK
	transport		
SANOP	Study of Abuse and Neglect of Older People	2006	UK



