

# **Disabilities, Independence and Dependency Situations Survey (DIDSS)**

## Methodology

Subdirectorato-General for Sectoral Social Statistics  
February 2010

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## 1 Introduction

The importance of the research on the number, characteristics and situation of persons with disabilities counts on a clear consensus in our society.

The demographic changes experienced in recent decades in Spain have brought with them a noticeable ageing and growth process that is increasingly accelerated. Medical advances and the evolution of the welfare state have translated into a strong increase in life expectancy. The increase in longevity has also coincided with important social changes, obligating social and political institutions to adjust their objectives to the new reality, which requires more social protection. This lengthening of life should not be associated merely with an increase in persons with disabilities, although this is one of the most influential factors.

To this end, the obtaining of adequate basic information regarding the situation of persons with disabilities, will allow the persons responsible for planning social policy to re-order the current social and health structures, through the development of programmes that adapt to the needs of fundamental services. It is essential to indicate the importance of the information for the development of the current Law on the Promotion of Personal Independence and Service to Persons in a Situation of Dependency (LAAD), which was passed in December 2006. The LAAD is prepared as a new social protection modality that expands and complements the protecting action of the State and of the Social Security System. It is also necessary to have a global vision of the needs for aid and support of persons in a dependency situation.

The Survey on Disabilities, Impairments and Health Status (SDIHS-99), which the INE conducted in cooperation with the IMSERSO and the ONCE Foundation in the year 1999, has contributed significantly to giving answers to these questions.

This growing interest in the integration of persons with disabilities in their own social environment also extends to the international scope. Already in the year 1982, the General Assembly of the United Nations, in its thirtieth period of sessions, adopted the World Programme of Action concerning Disabled Persons. Its fundamental objective was to promote efficient measures for the prevention of disabilities and for rehabilitation, and for achieving the objectives of the equality and full participation of those persons with disabilities in social life and development.

As a result, the National Statistics Institute (INE), the State Secretariat for Social Services, Families and Disability (through the Directorate General for the Coordination of Sectoral Policy for Persons with Disabilities and the IMSERSO), the ONCE Foundation, through the signing of a Partnership Agreement, have shared work, knowledge and experience, in order to carry out the new statistical operation regarding Disability, Independence and Dependency Situations.

This statistical operation is based on the experience of the former Survey on Disabilities, Impairments and State of Health, carried out in 1999, adapted to the

current social and demographic conditions and instilled with the philosophy of the new International Classification of Functioning, Disability and Health (ICF).

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## 2 DIDSS Working Group

In June of 2006, the INE, the IMSERSO and the Directorate General for the Coordination of Sectoral Policy for Disabilities agreed on the need and usefulness of carrying out a new disability survey that would provide the data necessary for the planning of prevention policies and social services, and that would provide statistical support for the Information System of the National System for the Autonomy of and Support for Dependent Persons.

As a result, the INE began the preparatory work for the new statistical operation, whose first stage, targeting households, was carried out during the November 2007 - February 2008 period. The second stage, aimed at persons resident in certain collective establishments, was carried out during the May-July 2008 period.

For the purpose of the objectives and the content of the Survey reflecting the real needs of those persons with disabilities, a multidisciplinary Working Group was created, in which technicians from the Ministry of Labour and Social Affairs participated, specifically from the IMSERSO and from the Directorate General for the Coordination of Sectoral Policy for Disabilities, representatives of the ONCE Foundation and the INE.

Subsequently, at the request of the ONCE Foundation, representatives from the CERMI (Spanish Committee of Representatives of Disabled Persons) and from the FEAPS (Spanish Confederation for Persons with Mental Retardation) were included in the Group.

### ***Specific agreements of the DIDSS working group***

Beginning with the contributions of the experts who participated in the Seminar, the Working Group began a round of 12 working sessions, whose first stage ended in February 2007, with the writing of a first draft of questionnaires of the DIDSSh-08. This first version of questionnaires was tested in the Pretest stage, and the results were analysed by the Working Group in two meetings (April-May), leading to the final version of the questionnaires, whose content includes the agreements arrived at by the Group. These can be summarised as:

### **Target study variables**

Before listing the target study variables, it is necessary to make some methodological points:

**Disability, according to the DIDSSh:** Although the ICF includes within the term *disability* all of the impairments, limitations of activity and restrictions of participation, in the DIDSSh-08, the concept of disability is identified with **important** limitations to carrying out everyday activities that have lasted, or are expected to last, more than one year, and whose origin is an impairment.

As was previously indicated, in the ICF, it is difficult to distinguish between "activities" and "participation", and therefore, the classification provides a single list of activities/participation, and leaves the decision to the user, depending on her/his own operative criteria, of differentiating between the two concepts. Along these lines, the decision made in the DIDSSh-08 has been to consider those activities relating to the first seven chapters of the nine in which the ICF groups the "Activities and Participation" component.

The two chapters that are not included correspond to "Main areas of life" (relating to activities necessary for participating in education, work, employment and economic activities) and "Community, social and civic life" (relating to activities for participating in the areas of free time and leisure, religious activities, political life and citizenship, etc.).

However, DIDSSh-08 has studied participation in these activities, through a group of questions targeting persons with disabilities, regarding their relationship with economic activity, education and social networks and contacts.

Once the importance limitations of activity are detected, it has verified, through the degree of severity of each one of the limitations indicated, whether said indications, for the purposes of DIDSSh, fulfilled the disability criterion (important limitations of activity), or did not due so due to being moderate or mild limitations. In this case, it is not considered disability.

As regards impairments, which the ICF includes under the umbrella term of disability, they are also a study target, but with one restriction: it only studies those impairments that have caused a limitation of the activity of the person.

Target study variables:

- Disabilities in persons 6 years of age and over, and limitations in children 0 to 5 years old.
- Characteristics of the disabilities and limitations: severity, technical aid and personal assistance, impairments, causes of impairments, age at beginning of disability / limitation and of impairment. Among the disabilities studied are those related to basic everyday activities, which are taken into consideration to recognise the right to assistance that the law foresees. In this way, the survey, though not providing the number of dependent persons according to the criterion of the law, does allow for establishing a bridge or nexus between the subjective perception and the objective measurement of the phenomenon.
- Relationship between persons with disabilities and the labour market and education; conditions of the dwelling and accessibility; characteristics of the carers; social, health and economic benefits; social networks and contacts; discrimination; private expenditure of households as a result of the disability and general health.

**Classification variables**

Age, sex, kinship relationships (with the household reference person and with the persons who have some disability), country of birth, nationality, marital status and cohabitation situation, level of studies completed, certificate of handicap ( $\geq 33\%$ ), relationship with economic activity, professional situation, occupation, activity in the company and province of residence.

**Differences in the formulation of disabilities (persons aged 6 years old and over) in SDIHS-99 (based on the ICDH) and in DIDSS-h 08 (based on the ICF)**

Although the formulation of disabilities of the SDIHS-99 already bore in mind the draft of the ICF, there are some differences with regard to the formulation of DIDSSh-08. The main differences have been:

1. Detection of persons with disabilities. SDIHS-99 detected persons with some disability by asking directly "if they had some kind of disability". DIDSSh-08 asks about limitations of activity, as is proposed by the ICF, to measure the negative aspects of the "activities and participation" component. Subsequently, through the degree of severity indicated by the person interviewed for each one of the limitations s/he has marked, it has been possible to verify if said limitations, for the purposes of DIDSSh, fulfilled the disability criterion: important limitations in activity or they did not fulfil it, due to being moderate or mild limitations. In this case, it is not considered disability.
2. Structure
  - The groups of disabilities (important limitations) considered practically coincide with those recognised in the SDIHS-99, although the DIDSSh-08 will use, as possible, the ICF terminology to name them.
  - As regards the disabilities that comprise each of the groups, the coincidence with the SDIHS-99 is not so evident. Some SDIHS-99 disabilities have been split according to ICF criteria, and new ones have been included on considering them of interest.
  - Remaining are those relating to vision and hearing, such as in the SDIHS-99, assuming that the ICF breaks with this, since in these cases, which is really asked is the impairment, and not the disability.
  - The number of disabilities has risen from 36 to 44. The DIDSSh-08 disability groups have been the following:

<b>DIDSSh-08</b>	<b>ICF Chapter (Activities and Participation)</b>	<b>SDIHS-99</b>
1. Vision	Body function (visual functions)	1. Sight
2. Hearing	Body function (auditory functions)	2. Hear
3. Communication	3. <i>Communication</i>	3. Communicate
4. Learning and application of knowledge and development of tasks	Part of chapter 1. <i>Learning and application of knowledge</i> and part of chapter 2. <i>Tasks and general requests</i>	4. Learn, apply knowledge and develop tasks (only mental functions)
5. Mobility	4. <i>Mobility</i>	5. Get around 6. Use arms and hands 7. Get around outside the home
6. Self-care	5. <i>Self-care</i>	8. Care for oneself
7. Home life	6. <i>Home life</i>	9. Perform housework
8. Interactions and interpersonal relationships	7. <i>Interactions and interpersonal relationships</i>	10. Relate to other persons

### **Differences between limitations (children 0 to 5 years old) in SDIHS-99 and DIDSSh-08**

After analysing the instrument for evaluating dependency from 0 to 3 years of age and the VINELAND questionnaire (scale that measures the social maturity of children), it was observed that both could serve as a complement, but they were not valid as a pattern for the objectives of DIDSSh-08. Therefore, the group agreed to continue with the scheme of the SDIHS-99, though it also decided to improve the wording of some of the questions, clarifying them according to the objectives, adding a reference age according to the criteria of the aforementioned instruments, and including or splitting up questions to complete the previous list of limitations.

### **Differences between impairments in DIDSSh-08 and the ICF**

Some of the impairments considered in SDIHS-99 (paraplegia, tetraplegia, ...) correspond to illnesses, and therefore, do not appear in the ICF as a function or as a structure. Bearing in mind that the fundamental target study variable in this



survey is disability; that the associating movements need impairment data based on the previous classification, since the most common questions are of the following type: How many deaf persons are there in Spain?, How many blind persons?, How many persons have an amputated limb?, etc.; and finally, given the importance of continuing the series begun with the SDIHS-99, the Working Group considered that, in matters of impairments, they should not require the application of the ICF.

### **Gender focus**

To consider the perspective of gender in policy design regarding disability is essential in advancing towards the equality of opportunity between men and women. This focus considers the different opportunities and needs that men and women have, not only due to their biological differences, but also because of the specific roles that they play in society, according to social and cultural patterns.

To this end, the Group has agreed to include in the survey a group of variables (relationship with economic activity, education, discrimination, social networks and contacts, social and health services, carers, etc. ) that allow for adequately reflecting the situations of equality or inequality due to gender.

Regarding the relationship with economic activity of persons with disabilities, it has studied just what this relationship is, if due to the disability, they have had to modify it or have had to change occupation, if they have ever worked the type of working day, form of access to employment, type of contract, reason for stopping working, time unemployed, whether they are looking for a job, type of job search, main reason why they believe they will not find work, reason why they are not looking for work. If the persons are not incorporated in the labour market, but carry out or have carried out unpaid work, especially in the area of housework, it is studied whether, faced with disabilities, they have had to stop carrying out certain tasks-work important or necessary for the household economy and which affect their social role (hanging the laundry, doing the grocery shopping, cooking, sewing, etc.).

Regarding education, it has studied whether they were undertaking some type of studies, and what they were, as well as the degree of school integration.

It also includes a section regarding discrimination due to disability.

The information regarding social networks and contacts can determine gender differences through questions such as free time activities that they carry out and activities that they would like to participate in but cannot.

The questions regarding health and social services reflect potential gender inequalities in the access to said services.

Finally, it deals with the subject of carers, allowing for ascertaining the role of women as informal caregivers and the consequences of providing this care on aspects of their family life, work life, or free and leisure time. Some of these carers also have disabilities. This group has been asked about the number of hours they spend providing care, the consequences that this activity of

caregiving has on their health (for example, the persons feel depressed or tired, etc.), ); they have also been asked about the consequences on professional aspects (they had to leave their work, problems with their work schedule, they had to reduce their working day, etc.) ); or about the consequences on leisure, free time or family life (they have not been able to have children, or form a family, they have problems with their partner, cannot go on holiday, etc.). ).

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### 3 DIDSS-08 Pretest

Given that the DIDSSh-08 included numerous innovations in its content, it has been essential to carry out an assessment process of the initial questionnaires, consistent not only in traditional quantitative field studies, as a pilot study, but also in qualitative studies, such as those known as "in-depth tests". It is convenient to use both methodologies in carrying out the pretest of the questionnaires, since each of them offers different and important information for increasing the quality of the questionnaires.

Therefore, the Pretest of the DIDSSh-08 has incorporated two strategies (pilot study and in-depth tests). The objective has been to obtain the greatest quantity and variety of evidence regarding the foreseeable functioning of the compiled questionnaires.

Among the innovations incorporated in the DIDSSh-08, there were three facts that could effect, in an important way, the comparability with the previous SDIHS-99. The first was the change in the conceptual framework (ICF): in the DIDSSh-08, the disabilities have been adapted to the ICF (they have gone from 36 disabilities in the SDIHS-99 to 44 in DIDSSh-08), and the formulation of the questions has been modified.

The second referred to the fact that the detection of the disabilities was done in the household questionnaire, and therefore, the person who provided the data regarding the persons who had some disability was an indirect informant or *proxy* (it was also done this way in the SDIHS-99), whereas in the disabilities questionnaire, this information was confirmed by the person with disabilities her/himself (in the SDISH-99, it was not confirmed, but rather, the answer of the *proxy* was accepted).

And the third responded to the recent passing of the LAAD. This had been in force for several months when the field work was performed, which could have led persons without disabilities to claim to have them, or persons with mild disabilities to claim a greater severity than the real severity, on being more sensitised by the media pressure accompanying the LAAD.

For these reasons, both the pilot study and the in-depth tests have been centred in the section on the detection of disabilities.

#### Pilot study

As a first strategy used in the test of the questionnaires, a pilot study has been carried out, aimed at a sample of approximately 2,000 persons, with the purpose of measuring whether the new formulation of the disabilities led to an excess of "false positives". For this, two alternative versions of the module on the detection of disabilities have been tested, one of the SDISH-99 formulation, and the other with the DIDSSh-08 (ICF) formulation.

The pilot study, carried out in April-May 2007, has also allowed us to adjust the times needed to carry out the work in each section, depending on the rate of "positive" answers obtained.

### **In-depth tests**

The in-depth tests have been carried out in cooperation with the University of Granada, in March and April 2007, in Madrid and in the Behavioural Observation Laboratory of the University of Granada.

The objective of the cognitive pretest procedures is to provide evidence that optimises the quality of the information provided by the questionnaires. The recommendations and proposals come from the evidence regarding the "question-and-answer process" of the surveyed persons to the questions provided by said procedures. The content of this evidence refers both to the cognitive process and to those "elements" of social interaction that are characteristic of the interview situation. Therefore, this is not only a matter of controlling possible sources of errors in measurement due to defects in the phrasing of the questions, the design of the questionnaire, etc., plus the possible interactions among them, but also of obtaining information regarding the expectations of the surveyed persons, the role taken on during the interview, the anticipated consequences of the assessment, etc., that might introduce errors of measurement in the desired interpretation of the answers.

The cognitive pretest procedures have been applied to the section of the detection of disabilities.

The "cognitive pretest" label groups a whole set of specific procedures, which in the case of the DIDSSh-08 questionnaire, are:

- I. Behavioural encoding: The behavioural indicators registered during the interaction between the interviewer and the interviewee allow for identifying "problematic" questions. This also allows for registered errors in the format of the task, instructions for the registration of the answers, time of execution, etc.
- II. Cognitive interviews: These provide direct evidence regarding the development of the phases of the "question-and-answer" process implemented by the interviewees: errors of comprehension, recovery in the memory of the required information, mistakes in the compilation, and incongruencies in the communication, of the answer.
- III. Discussion groups with "surveyable persons": Perspective and contents of the "role" of survey participants; knowledge and comprehension of the most

general concepts; attributes regarding the objective and purpose of it; attitudes and degree of implication, etc.

It was decided to use these three procedures, focusing on the objectives of the pretest and the administrative method of the final survey: personal interview with print questionnaires.

On the other hand, given the importance and complexity that the detection of the disabilities was for the Survey, special attention has been paid in the pretest of the design of said questions, the compilation of adequate introductions, and application procedure, etc. From there onwards, we have the need to obtain evidence regarding their functioning in the context of a survey study.

The total number of participants in the cognitive interviews has been 50 persons: 10 from the general population, 20 persons with disabilities and 20 relatives of the persons with disabilities.

The selection of the participants has been done with a profile defined by the variables of sex, age (between 16 and 70 years old) and level of studies. In addition to these criteria, all of the participants were selected in such a way that, by their situation, they could be "surveyed" in the DIDSSh-08 (functional level of Spanish, etc.).

The number of participants in the discussion groups has been 24, distributed in three groups with eight persons in each. The first group was made up of the main carers, the second of the persons without disabilities and the third of the persons with some disability.

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## **4 The DIDSSh-08 survey**

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### **1 Objectives**

The overall objective of the Survey is to fulfil the demand for information for the National System for the Autonomy of and Support for Dependent Persons (SAAD), providing a statistical base allowing for guiding the promotion of personal autonomy and the prevention of situations of dependency.

### **Specific objectives:**

1. To estimate the number of persons with disabilities who resided in Spain in family dwellings, as well as their geographical distribution.
2. To ascertain the limitations of activity and the restrictions of participation in the everyday situations of the persons, as well as the severity of said limitations.
3. To ascertain the characteristics of persons with disabilities and in a situation of dependency.
4. To identify the different types of impairments that cause the limitations.
5. To ascertain the causes that have generated said impairments.
6. To evaluate the equality of opportunity / discrimination of persons with disabilities in the areas of labour, education, recreation, mobility, etc.
7. To identify the needs and demands for assistance, as well as the aid that they receive and its characteristics. To ascertain the use of technical help, special adaptations (in the household, the workplace, etc.), personal care, etc.
8. To carry out the analysis of the disability from the perspective of gender.

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## **2 Study focus**

The need for updated information on persons with disabilities is evident, not only because dependency has taken on the dimension of a first magnitude social problem, but also because the concept of disability has changed.

The ICIDH of 1980 has been reviewed in depth, and in the year 2001, the WHO published the second classification: **International Classification of Functioning, Disability and Health (ICF)**. *Disability* is considered to be an umbrella term encompassing impairments, disabilities (now limitations of activity) and handicaps (now restrictions of participation), and introduces another crucial difference regarding the previous ICIDH: the ICF expands the concept of health, by incorporating environmental factors (physical, social and attitudinal environment in which the persons live and carry out their lives).

The main objective of this classification is to provide a common and standardised language and a conceptual framework for the description of health and the states related to health. This is to say, the ICF has gone from a classification of the consequences of illness, to a classification of the components of health.

Among its applications is its use as a statistical tool in the collection of population survey data. In this sense, at the end of the year 2006, the Popular Parliamentary Group in the Congress presented a non-Law Proposition regarding the future Survey on Disability, Independence and Dependency Situations, for debate in the Non-Permanent Commission for Integral Policy on Disability. In the presentation of reasons, the need was expressed for the data collection system

of the new survey and its results to be as coherent as possible with the parameters of the ICF.

In turn, there are several international projects whose objective is the development of disability questionnaires, based on the ICF. For example, the Washington Group for the Measurement of Disability, promoted by the United Nations, has been working for years on the definition of a *general measurement of disability* to include in censuses or surveys, and will continue with the development of an *extended measurement of disability* for specific surveys.

The part of the ICF that deals with *functioning and disability* has two components:

- *Functions of the systems and structures of the body*

The *functions of the body* are those physiological functions of the systems of the body. The *structures of the body* are those anatomical parts thereof.

**Impairments** are problems with these functions or structures.

- *Activities and participation*

*Activity* is the performance of a task on the part of an individual.

*Participation* is the act of becoming involved in a vital situation.

**Limitation of activity** is the difficulty that a person has, on an individual level, in the intent / carrying out of an activity.

**Restriction of participation** is the difficulty that a person may have on becoming involved in a situation from a social perspective.

The ICF includes, under the global concept of **disability**, all of the impairments, limitations of activity and restrictions of participation. However, the Classification itself indicates that it is difficult to distinguish between "activities" and "participation", and likewise, between "individual" and "social". Because of this, it provides a single list of activities/participation, and leaves the decision to the user, depending on his/her own operative criteria, of differentiating between activities and participation.

### **Basic clarifications**

1. Beginning with the basis that a disability is defined as any important limitation to carrying out an activity, which lasts or is expected to last more than one year, and whose origin is an impairment, it must be considered that persons, in general, are able to carry out endless activities, but for the purposes of this Survey, only a limited number of these activities were collected (the most basic and common activities).

Therefore, if a person did not have enough difficulty in carrying out any of the 44 activities appearing in the survey (without external technical assistance or personal help), s/he was considered to be a person without disabilities.

2. The purpose of this group of disabilities is to determine whether a person, due to a health problem or a disability, has difficulties in carrying out (even hypothetically) certain tasks, even if in practice, and due to other conditioning factors outside of the health field, s/he has never carried them out.

This would be the case, for example, of the Disability to carry out household chores, of certain elderly men. Sometimes, situations are presented in which the person her/himself, and even her/his relatives, does not consider the possibility of being able to have this disability, given that mainly due to cultural factors, the person has never carried out these tasks. Nonetheless, the concept of disability centres on the idea of impairment as the possible origin of disability, that is, it tries to analyse whether the person is able to carry out a certain activity, irregardless of whether s/he actually practices it or not.

3. It is also necessary to bear in mind that disabilities might not appear alone, but rather, an individual person may have two or more disabilities that may be independent of others (being caused by different impairments), or they may have their origin in a single impairment. For the purposes of this Survey, all of the disabilities occurring in each individual person were collected.

@ Each disability may only be caused by an impairment. The means of determining which impairment is the most adequate in each individual case was specified with objective and comprehensive norms.

4. Apparently important impairments, as could be the case of a very noticeable limp, might, in fact, not severely limit the behaviour of a person, and conversely, and therefore, the Survey clearly indicated that it only included the disability when the interviewee her/himself considered that the impairment was severely limiting some of her/his activities. It was thus based on the subjective perception of the person her/himself, of her/his situation.

@A disability was the target of study, depending on the time or permanence thereof, considering specifically those that had lasted or were expected to last more than one year. This Survey was therefore not interested in those passing limitations that could be due to a clearly resolvable situation, as could be the case of a limitation caused by a broken leg or the like.

In any case, we must point out that certain disabilities caused by certain disorders (for example: schizophrenia, depression, labyrinthine vertigo, etc.) usually appear repeatedly in the life of the individual, in determined periods known as crises. They were considered disabilities so long as the sum of these crisis periods was greater than one year, given that the duration requirement did not necessarily imply that the disability had to be continuous over time.

5. All of the disabilities of the persons were studied, even if they were overcome with the use of some type of technical aid. In this sense, it is important to point out that the study only considered to be disabilities those that were managed

through the use of external technical aid (crutches, wheelchairs, prostheses that substitute for an extremity, hearing aids, oxygen, catheters, etc.), excluding those others that had been managed through the use of internal technical aid (pacemakers, intra-ocular cataract lenses, articular knee prostheses, cardiac valves, cerebral decompression valves, nails, etc.).

Thus, for example, a person who, with the help of a pacemaker, did not have any type of difficulty in carrying out the everyday activities studied, that is, who had managed the disability with the use of the pacemaker (internal technical aid), was not considered to have a disability. Now, if this person, who had a pacemaker implanted, was limited in carrying out any of the activities, even with the use of this internal technical aid, then s/he was considered to have a disability.

Conversely, a person who, with the use of a wheelchair or an orthopaedic leg (external technical aid) did not have any type of difficulty in carrying out the activities studied, was considered to have a disability.

An exception was made in the case of visual disabilities: this only included the disabilities that remained with the use of glasses or lenses, and not those that had been managed with the use of these technical aids, even though they were external.

6. Regarding the differences based on age, two age groups were considered. The first group was comprised of persons 0 to 5 years old, and the second group was comprised of persons 6 years old and over.

For the first group, that is, for children under 6 years of age, the detailed study of disabilities was not used, given the difficulty of their detection. They did, however, study possible limitations that may have been detected in the children at this age.

- In conclusion, for each person interviewed, all of the disabilities that had lasted or were expected to last more than one year, and whose origin was an impairment, were included, determining a single impairment for each disability. It was also considered that a person had a disability, even if it was overcome with the use of external technical aid, only in the case of disability to see if there would be an exception, granted that the use of glasses or contact lenses is very generalised, recognising only the disabilities that subsisted with the use of glasses or contact lenses.

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#### **5.4 Survey stages**

Having defined the concept of disability, which is the starting point of the research, we have proposed the carrying out of the DIDSSh-08 study in three phases, identified with the following questionnaires: one Household Questionnaire, two individual questionnaires (Disability Questionnaire for



persons 6 years old or over and Limitation Questionnaire for children 0 to 5 years old) and a Questionnaire aimed at those persons who are the main carers.

### **First phase. Household Questionnaire**

In the first phase, we have tried to include all of the persons of the household interviewed who had some disability. To this end, we have gone to the reference person of the household, her/his spouse or partner, or another person who was in the household at the time, and who was sufficiently informed, to ask a series of questions aimed at determining the disabilities of each person resident in the household, where the disability was shown in terms that were comprehensible for persons of any cultural level.

In this first phase, information was also requested regarding the type of household and composition thereof, regarding the regularly monthly household income level and extraordinary social benefits.

Likewise, information was requested of all of the residents of the household regarding age, sex, kinship relationships - with the reference person of the household and with the persons who had some disability - , country of birth, nationality, marital status and cohabitation situation, level of studies completed, certificate of handicap ( $\geq 33\%$ ), relationship with economic activity, professional situation, occupation, activity of the company and province of residence.

It ended with a section regarding the conditions and accessibility of the dwelling, and other regarding private household expenditure due to the disability.

### **Second phase**

#### **A. Disability Questionnaire (Persons 6 years old or over).**

This second phase aimed at interviewing persons 6 years old and over where were the target of study, that is, who presented some disability. Therefore, a questionnaire of Disabilities was given to each one of the persons 6 years old or over who had stated, in the household questionnaire, that they had some disability.

This questionnaire was to be answered, whenever possible, by the target person of the interview. In this case, the completion of the questionnaire was begun, verifying the disabilities that the informant of the household questionnaire had marked. Next, they were asked about the characteristics of the disabilities: degree of severity of each disability, age at the beginning of the disability, impairment that caused each one of them, and whether they received supervision or personal assistance, or used some external technical aid.

For each disability, only one impairment was considered. Therefore, when the same disability could be caused by more than one impairment, or when it was difficult to ascertain the true origin of the disability, at the time of collecting this information, certain guidelines, which will be explained later, were followed.

Once the disabilities caused by the same impairment were determined for each person, and starting from this point, they were asked about the problem that

caused said impairment, and the age at which it began. Likewise, information was requested regarding a set of diagnosed illnesses; whether the disabilities forced the person to observe bedrest; regarding the degree of satisfaction with the technical and/or personal aid received; personal care; changes of residence due to disabilities; belonging to non-governmental organisations; health and social benefits, if they had received or were receiving some type of economic benefit.

In order to analyse the degree of social integration of the group of persons with disabilities, a section was introduced regarding changes in economic activity as a result of the disability, and data regarding the current economic activity. Likewise, it was studied whether the persons who were not incorporated into the labour force had had to leave certain tasks-jobs that were important or necessary for their household economy, as a result of the disability. More specific information was also required regarding the level of studies completed, studies currently undertaken and school integration.

It also included sections regarding discrimination, social networks and contacts, accessibility and overall health.

#### **B. Limitation Questionnaire (Children 0 to 5 years old).**

This questionnaire was aimed at the population of children under 6 years of age who had some target limitation of study of the Survey.

A Limitation questionnaire was opened for each child under 6 years of age, who in the household questionnaire appeared as having some limitation of those studied, and this questionnaire was to be answered by the parents or guardians of the child.

As with the Disability Questionnaire, information was requested regarding limitations; the impairments that had caused them (in the case of children under 6 years of age, the list of impairments is not as comprehensive as those considered in persons 6 years old and over, due to reasons of statistical significance). They were also asked about the severity, the technical aid and personal assistance (received and not received), the age at the beginning of the limitation and of the impairment. This studied the main cause of the impairments, the age and the beginning of them and the diagnosed illnesses.

Lastly, it obtained information regarding changes of residence due to some limitation of the child; belonging to non-government organisations and regarding health, social and economic benefits.

#### **Third phase. Main Carer Questionnaire**

A specific questionnaire was introduced regarding the characteristics of the persons who were carers, and which was to be answered, whenever possible, by the main carer. The goal was to obtain information on the demographic and social characteristics of the main carers; on the degree of professionalisation, the time dedicated and the type of care, regarding the difficulties in providing the care, their state of health, and professional, family or leisure aspects that they had to dispense with in order to dedicate themselves to providing care.

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## **4 Scope of investigation**

### **Population scope**

The research has targeted the set of persons who resided in main family dwellings. When a single dwelling was comprised of two or more households, the study included all of them, but independently for each household.

### **Geographical scope**

The Survey has been carried out throughout the entire country.

### **Time scope**

The information collection period has covered four months, from October 2007 to February 2008.

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## **5 Sample design**

### **Type of sampling**

A stratified two-stage sampling has been used. The first-stage units are the census sections. The second-stage units are the main family dwellings. No sub-sampling at all has been performed within them, studying all of the households and persons with their regular residence therein.

The framework for the sample selection has been the framework of areas made of up the listing of census sections existing with reference to 1 April 2007. In the case of the second-stage units, we have used the listing of main family dwellings in each of the sections selected for the sample.

In each province, an independent sample has been designed to represent it, on one of the objectives of the survey being to provide data with this breakdown level.

### **Stratification**

Two types of municipality have been considered in compiling the strata:

*Self-represented municipalities* Those municipalities that, given their category within the province, should always have sections in the sample.

Self-represented municipalities are:

-The provincial capital

-Municipalities with a noteworthy demographic situation within the province

*Co-represented municipalities* Those municipalities that, within the province, are a part of a group of demographically similar municipalities, and are represented in common.

In agreement with this classification, the **strata** considered are as follows:

**Stratum 1.** Provincial capital municipality

**Stratum 2.** Self-represented municipalities, important as compared with the capital.

**Stratum 3.** Other self-represented municipalities, important as compared with the capital or municipalities with more than 100,000 inhabitants.

**Stratum 4.** Municipalities with between 50,000 and 100,000 inhabitants.

**Stratum 5.** Municipalities with between 20,000 and 50,000 inhabitants.

**Stratum 6.** Municipalities with between 10,000 and 20,000 inhabitants.

**Stratum 7.** Municipalities with between 5,000 and 10,000 inhabitants.

**Stratum 8.** Municipalities with between 2,000 and 5,000 inhabitants.

**Stratum 9.** Municipalities with fewer than 2,000 inhabitants.

It must be considered that, given the different distribution of sizes of the municipalities in the provinces, it has not been possible to carry out a uniform stratification for all of them. For example, the province of Lugo has only 16 municipalities with fewer than 2,000 inhabitants, and therefore, theoretical strata 8 and 9 have been grouped into stratum 8, which contains those municipalities with fewer than 5,000 inhabitants. Nonetheless, whenever possible, we have tried to carry out a uniform stratification for all of the provinces belonging to the same Autonomous Community.

### **Sample size. Allocation and time distribution**

In order to cover the objectives of the survey, to provide estimates with a given degree of reliability on national, Autonomous Community and provincial levels, and bearing in mind the precision of the results obtained in the previous disability questionnaire carried out in 1999, we have determined an initial sample size of 88,725 dwellings, distributed among 3,550 census sections, with **25** being the number of dwellings interviewed in each section.

Beginning with the previous size, and so as to meet the needs of some Autonomous Communities of obtaining more broken-down data, the size was increased to reach a final sample size of 96,075 dwellings, distributed among **3,843 sections**.

For the distribution of the sample of sections between provinces, we have considered the need of providing estimates with an acceptable precision in each and every one of them, regardless of their size, and at the same time maintaining the reliability of the estimates on a national level. In this sample distribution study, with the previously mentioned objectives, the information provided by the last disability survey of 1999 has proven extremely useful. Specifically, we have analysed the provincial estimates of the number of persons with disabilities, and the precision obtained in terms of variation coefficient, correcting on one direction or the other the sample allocation, depending on this information.

In this way, part of the sample has been assigned to each province, uniformly, and the rest proportional to its size, measured by the population residing therein.

The distribution by strata, within each province, has been carried out proportionally to the population size of the stratum.

The distribution of the sample of sections by province and stratum has been as follows:

**Chart 1. Distribution by stratum of the sample of sections**

Province	1	2	3	4	5	6	7	8	9	Total
01 Álava	37						9			49
02. Albacete	20				12		3	7	7	49
03. Alicante	19	13		21	24	13	9	3	3	105
04. Almería	24			19	6	11	6	11		77
05. Ávila	15						15		19	49
06 Badajoz	12			4	7	5	10	10	8	56
07. Baleares	29				23	13	6	6		77
08. Barcelona	67		47	34	31	20	15	7	3	224
09. Burgos	23				10		4		12	49
10. Cáceres	13				5	6	6	9	17	56
11 Cádiz	13	20	10	40	16	10	10			119
12. Castellón	17				21	4	5	4	5	56
13. Ciudad Real	8	6			10	13	8	5	6	56
14. Córdoba	36				21	8	11	12		91
15. La Coruña	17			12	15	10	16	7		77
16 Cuenca	12					11		6	20	49
17. Girona	7				17	8	9	8	7	56
18. Granada	28			6	8	19	11	11	8	91
19. Guadalaíara	18				6		13		12	49
20. Guipúzcoa	15			5	9	15	6	6		56
21 Huelva	24				32		7	14		77
22. Huesca	14					17	5	27		63
23. Jaén	15	8			16	13	9	16		77
24. León	15	8			6		13		14	56
25. Lleida	18					7	8	8	15	56
26. La Rioja	27				9		6	7	7	56
27. Luqo	13					9	7	20		49
28. Madrid	129		45	32	17	8	14			245
29. Málaga	48			38	21	5	14			126

30. Murcia	30	15	10	23	14	6			98	
31. Navarra	29			9	27		47		112	
32. Ourense	16				6	6	11	10	49	
33. Asturias	15	19	6	12	14	5	6		77	
34. Palencia	23					8	18		49	
35. Las Palmas	29		15	13	15	5			77	
36. Pontevedra	6	22		13	16	7	6		70	
37. Salamanca	22				6	6		15	49	
38. S <sup>a</sup> Cruz Tenerife	18	11	25		11	8	4		77	
39. Cantabria	20	6		7	10	5	9	6	63	
40. Segovia	17					7	7	18	49	
41. Sevilla	58		15	30	17	13	7		140	
42. Soria	20					12		17	49	
43. Tarragona	10	8		12	7	6	7	6	56	
44. Teruel	15				21			27	63	
45. Toledo	7	8			9	7	16	9	56	
46. Valencia	39		13	29	15	9	8	6	119	
47. Valladolid	35			4		9		8	56	
48. Vizcaya	24	6	6	19	8	7	7		77	
49. Zamora	16				7		26		49	
50. Zaragoza	50			5		8		7	70	
51. Ceuta	21								21	
52. Melilla	21								21	
Total	1277	150	102	301	518	431	389	383	292	3843

Within each section, and for the purpose of attaining a greater representation of the children under six years of age with disabilities, we have encouraged, in the sample, the presence of dwellings in which, according to register data, there is a child, rather than being strictly proportional.

Sample of <b>3,843</b> sections	Dwellings with a child under 6 years of age	Dwellings without a child under 6 years of age	Total
Strictly proportional distribution	11,618	84,457	96,075
Sampling distribution encouraging the presence of children under 6 years of age in the sample	15,090	80,895	96,075

Due to this non-proportional distribution, the sample of dwellings is not self-weighted within each stratum, granted that those dwellings in which there is a

child will have a greater probability of belonging to the sample. This fact has been considered in the construction of the estimators.

The time distribution of the sample has been carried out as homogeneously as possible, bearing in mind the availability of interviewers in the different provinces. The summary of this distribution, by province and week, appears in the following table:

**Chart II. Distribution, by week, of the sample of sections**

<b>Province/Week</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>Total</b>
01. Álava	7	7	6	5	6	6	6	6	49
02. Albacete	7	6	6	5	6	6	7	6	49
03. Alicante	15	13	13	12	13	13	13	13	105
04. Almería	11	10	10	8	10	10	9	9	77
05. Ávila	7	7	6	5	6	6	6	6	49
06. Badajoz	8	7	7	6	7	7	7	7	56
07. Baleares	10	10	10	9	9	9	10	10	77
08. Barcelona	28	28	28	28	28	28	28	28	224
09. Burgos	7	7	6	5	6	6	6	6	49
10. Cáceres	8	7	7	6	7	7	7	7	56
11. Cádiz	17	14	16	13	15	14	15	15	119
12. Castellón	8	7	7	6	7	7	7	7	56
13. Ciudad Real	8	7	7	6	7	7	7	7	56
14. Córdoba	12	12	11	10	11	11	12	12	91
15. La Coruña	10	10	10	9	9	9	10	10	77
16. Cuenca	7	7	6	5	6	6	6	6	49
17. Girona	8	7	7	6	7	7	7	7	56
18. Granada	12	12	11	10	12	12	11	11	91
19. Guadalaíara	7	6	7	5	6	6	6	6	49
20. Guipúzcoa	8	7	7	6	7	7	7	7	56
21. Huelva	12	10	10	8	9	9	9	10	77
22. Huesca	9	8	8	7	8	8	8	7	63
23. Jaén	10	10	9	8	10	10	10	10	77
24. León	8	7	7	6	7	7	7	7	56
25. Lleida	8	7	7	6	7	7	7	7	56
26. La Rioja	8	7	7	6	7	7	7	7	56
27. Luqo	7	6	6	5	6	7	6	6	49
28. Madrid	32	31	31	29	30	30	31	31	245
29. Málaga	17	15	16	15	16	15	16	16	126
30. Murcia	13	13	12	12	12	12	12	12	98
31. Navarra	15	14	14	13	14	14	14	14	112
32. Ourense	7	6	6	5	7	6	6	6	49
33. Asturias	11	10	10	8	9	9	10	10	77
34. Palencia	7	6	7	5	6	6	6	6	49
35. Las Palmas	11	10	10	9	10	9	9	9	77
36. Pontevedra	10	9	9	8	8	8	9	9	70
37. Salamanca	7	7	6	5	6	6	6	6	49
38. S <sup>a</sup> Cruz Tenerife	11	10	9	8	9	10	10	10	77
39. Cantabria	9	8	8	7	7	8	8	8	63
40. Segovia	7	6	6	5	7	6	6	6	49

41. Sevilla	19	17	18	15	17	18	18	18	140
42. Soria	7	6	6	5	6	6	6	7	49
43. Tarragona	8	7	7	6	7	7	7	7	56
44. Teruel	9	7	8	7	8	8	8	8	63
45. Toledo	8	7	7	6	7	7	7	7	56
46. Valencia	15	15	15	14	15	15	15	15	119
47. Valladolid	8	7	7	6	7	7	7	7	56
48. Vizcaya	10	10	10	9	9	9	10	10	77
49. Zamora	7	6	6	5	6	6	7	6	49
50. Zaragoza	10	9	9	8	8	8	9	9	70
51. Ceuta	3	3	3	3	2	2	3	2	21
52. Melilla	3	2	3	3	2	2	3	3	21
Total	531	487	485	427	474	473	484	482	3843

### Sample selection

The sections have been selected within each stratum with a probability proportional to their size. The dwellings, in each section, with the same probability via random start systematic sampling

### Estimators

In order to estimate the main characteristics studied in the survey, we have used ratio estimators to which calibration techniques are applied.

The estimators have been calculated on a provincial level

The final estimator is obtained in several steps:

#### 1.- Estimator based on the sample design

The probability of belonging to the sample of a dwelling  $i$  in section  $S$  of stratum  $h$  is given by:

$$P(V_{ish}^t) = \frac{n_h V_s}{V_h} \cdot \frac{m_s^t}{V_s^t}$$

where:

$n_h$ : Number of sample sections in stratum  $h$ .

$V_s$ : Dwellings in section  $S$  of stratum  $h$

$V_h$ : Dwellings in stratum  $h$ .

$m_s^t$ : Theoretical dwellings of the sample in section  $S$  and that belong to group  $t$ . Super-index  $t$  refers to whether the dwellings has children or not. ( $t=1$  indicates that it is a dwelling with children, and  $t=2$  indicates without children)



$V_s^t$ : Dwellings of group t in section S.

To achieve the objectives of the survey, we have increased the sample of dwellings with children by 30% with regard to the number of dwellings that would have corresponded in a proportional distribution. Therefore,

$$m_s^1 = 1,3 \cdot 25 \cdot \frac{V_s^1}{V_s} \text{ y } m_s^2 = 25 - 1,3 \cdot 25 \cdot \frac{V_s^1}{V_s}$$

Due to the above, the sample of dwellings is not self-weighted on a stratum level.

The elevation factor from the sampling design for dwelling i of group t has the following expression:

$$f_i^t = \frac{V_h \cdot V_s^t}{n_h \cdot V_s \cdot m_s^t}$$

All of the dwellings of group t in the stratum have the same elevation factor.

## 2.- Correction of non-response

The classes used in the correction of non-response have been, within each province, the crossing of stratum, group to which the dwelling belongs and size of the dwelling.

The sizes considered have been:

Dwellings from group t=1 (dwellings with children): 1, 2, 3 and more persons

Dwellings from group t=2 (dwellings without children): 3 persons or fewer, and more than 3 persons

The corrected elevation factor for a dwelling of class C has the following expression:

$$k_{i,c}^t = f_i^t \cdot \frac{\sum_c^{m_s^t} f_i^t}{\sum_c^{m_{(e)s}^t} f_i^t}$$

The sum of the numerator extends to all of the dwellings of the theoretical sample of class C, and the sum of the denominator extends to all of the dwellings of the effective sample of class C.

The estimator of characteristic X in province P shall be:

$$\hat{X}_P = \sum_t \sum_c \sum_i k_{i,c}^t x_{i,c}^t$$

In which  $x_{i,c}^t$  the total persons in dwelling  $i$  of class  $C$  and of group  $t$  that has characteristic  $X$

### 3.- Calibrated estimator.

The final estimator is obtained by adjusting the previous factor for balancing the sample to the population, by age group and sex, that is, finding a new weight  $d_{i,c}^t$  in such a way that the following is checked:

$$\hat{P}_{(es)} = \sum_t \sum_c \sum_i d_{i,c}^t \cdot p_{i,c}^t(es) = P_{(es)}$$

where:

$\hat{P}_{(es)}$  = Estimated total persons who belong to age and sex group (s) in province P. Five-year age groups have been used.

$P_{(es)}$  = Demographic projection of the group (s) population in province P.

$p_{i,c}^t(es)$  = Total persons in the sample in dwelling  $i$ , class  $C$  and group  $t$  that belong to the age group and sex (es).

This calibration has been carried out by means of the CALMAR framework of the French National Statistics and Economic Studies Institute (INSEE).

### Sample errors

For the estimating of sampling errors, the **Jackknife method** has been used, allowing for obtaining the estimate of the variance of the estimator of characteristic  $Y$  through the expression:

$$\hat{V}(\hat{X}) = \sum_h \frac{n_h - 1}{n_h} \sum_{i \in h} (\hat{X}_{(ih)} - \hat{X})^2$$

where  $\hat{X}_{(ih)}$  the estimation of characteristic  $X$ , obtained by removing section  $i$  from stratum  $h$ , and  $n_h$  is the number of sections assigned in stratum  $h$ .

To obtain the estimator, and for simplicity's sake, rather than recalculating the elevation factors, the stratum factors are multiplied where the sections have been removed by the factor:  $\frac{n_h}{n_h - 1}$ .

In accordance with the above:

$$\hat{X}_{(ih)} = \sum_{j \neq h} F_j x_j + \sum_{\substack{j \in h \\ j \neq ih}} F_j \frac{n_h}{n_h - 1} x_j$$

The relative sampling error is published in the tables as a percentage, variation coefficient, whose expression is:

$$CV(\hat{X}) = \frac{\sqrt{\hat{V}(\hat{X})}}{\hat{X}} \cdot 100$$

The sampling error facilitates obtaining the confidence interval, within which, the real value of the estimated characteristic is found with a certain probability.

Sampling theory determines that, in the interval between

$$\left( \hat{X} - 1,96 \sqrt{\hat{V}(\hat{X})} \quad , \quad \hat{X} + 1,96 \sqrt{\hat{V}(\hat{X})} \right)$$

there is 95 percent confidence in finding the real value of parameter  $X$ .

Thus, for example, the estimated total persons between 6 and 64 years old, with some disability caused by a mental impairment was 324,200, with a relative sampling error of 3.13 percent. This implies that there is a high degree of confidence, in terms of a probability of 95 percent, of which true total is between the values of 304,311 and 344,089.

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## **6 Collection of the information**

### **Collection system**

The period of time during which the information was collected lasted 4 months (November 2007 - February 2008).

The information collection method has been the personal interview, which could be complemented, when necessary and in exceptional cases, via telephone interview.

The interviewers visited the dwellings in order to conduct the interviews and complete the questionnaires, according to the previously assigned work quota. In each centre, the visits necessary were made to obtain the required information, completing the interview with telephone calls in those cases in which it was necessary to complete omitted data or correct erroneous data.

### **Basic units**

#### **- *Family dwelling***

A family dwelling is considered to be any room or set of rooms and their outbuildings which occupy a building or a structurally separated part of the same and that, by the way in which they have been constructed, reconstructed or transformed, are destined to be inhabited by one or several households, and on the date of the interview are not used totally for other purposes. This definition includes:

Fixed dwellings: areas which do not respond totally to the definition of family dwelling, due to their being semi-permanent (huts or cabins), improvised with waste material such as tins and boxes (huts or shacks), or not having been conceived at the beginning for residential purposes, nor reformed to be used for these purposes (stables, mills, garages, storage units, caves, natural refuges), but which, nevertheless, constitute the main and habitual residence of one or more households.

Dwellings of a family nature existing within collective dwellings, so long as they are for the managing, administrative or service personnel of the collective establishment.

#### **- *Household.***

A household is defined as a person or group of persons who habitually reside in a family dwelling, and share food or other goods paid for within the same budget. Also considered members of the household are those employed persons resident in the same, and fixed guests resident in the household. If two or more human groups with different budgets reside in the dwelling, each of them comprises a household.

Included in this definition are private households that take root in collective dwellings, as long as they have autonomy in spending with regard to the group household.

- *Members of the household.*

The conditions established to determine whether or not a person is a member of the household, try to avoid the possibility of the same person being classified in more than one household, or on the contrary, not being classified in any household.

A person is considered to be a *member of the household* when s/he resides or plans to reside habitually in the household during the reference period of the survey (between 1 November 2007 and 29 February 2008).

Also considered to be members of the household are those persons who:

- Do not reside habitually in the surveyed dwelling, residing in a collective establishment, but plan to return to the household to reside therein before the end of the reference period.

- Are guests and persons employed in the household who reside therein.

A person considered to be employed in the household is any person who renders domestic services to the household, in exchange for previously stipulated payment in cash or in kind (such as chauffeurs, maids, domestic staff, carers, etc.).

A guest is any person who shares food with the household and/or inhabits the dwelling, providing a previously stipulated monetary payment for the household, with the household seeking profitable aims as a result of her/his stay.

Two different situations must be distinguished as regards guests:

- If a household resides habitually in the dwelling, as well as five or a smaller number (5 or fewer) of guests, each of said guests should be included therein.

- If a household resides habitually in the dwelling, as well as more than five guests (6 or more), the latter should not be considered belonging to the interviewed household, and therefore, the survey should not be conducted for any of these guests.

If the employed person or guest does not habitually reside, nor plans to reside, in the household for most of the reference period, s/he should not be considered a part of the household for the purposes of this survey.

If the employed person or guest does habitually reside, or plans to reside, in the household for most of the reference period, then s/he is considered an employed person resident in the household or a fixed guest.

- Persons who reside in different dwellings successively, but during the residence period, have resided in the surveyed dwelling longer than in any other family dwelling, or plan to reside in the surveyed dwelling for all or the longest part of the period (in case they have constituted a new household due to marriage or emancipation).

In agreement with this definition, it should be observed that:

Members of the household are considered to be those persons, of any age, who meet the established conditions, including newborns.

Members of the household may be present in, or temporarily absent from, the surveyed dwelling.

- *Collective establishment*

A collective establishment is a dwelling or building designed to be inhabited by a group of persons who do not constitute a household, subjected to a common authority or scheme, or linked by personal objectives or interests (hospital establishments, boarding schools, institutions for the elderly or for persons with disabilities, military establishments, etc.). This also includes all types of accommodation establishments.

- *Household reference person.*

The household reference person is considered to be that person who, habitually residing in that household, is the person who periodically provides the most to the household budget.

If the household reference person who provides the greatest income is not a member of the same according to the aforementioned definition, s/he cannot be considered the reference person, and therefore, the reference person will be that member of the household in whose name the monetary transfers from the person providing the greatest interest are made. In the case that the person receiving the transfers is underage, the reference person will be the member of the household who is responsible for the minor.

### **Incidences in the sample and treatment**

Incidences are considered to be the different situations that interviewers may come across during their work in a section selected for the survey.

There are three types:

- 1.- Incidences concerning dwellings
- 2.- Incidences concerning households
- 3.- Incidences concerning persons

- *Incidences concerning dwellings*

Every dwelling, in accordance with the situation in which it is found, is classified as:

- Surveyable dwelling

That which is used all or most of the year as a regular residence. Considering a dwelling as surveyable is the step prior to conducting the interview.

- Empty dwelling

The dwelling selected is uninhabited due to death or because the persons who lived there have changed addresses, it is in ruins or it is a temporary dwelling.

- Unlocatable dwelling

The dwelling cannot be located at the address that appears on the list of selected dwellings, either because the address is wrong or because the dwelling no longer exists, or for other reasons.

- Dwelling intended for other purposes

The dwelling selected is used completely for purposes other than a family residence, due to an error in the selection or because its purpose has changed, and therefore it does not form part of the population under study.

- Inaccessible dwelling

That which cannot be accessed to conduct the interview, due to climate causes, floods, etc., or geographical causes, when there are no transitable routes to reach it.

- Previously selected dwelling

This takes place when a dwelling that has previously been selected (less than five years prior) in any other survey is selected once again.

- *Incidences concerning households*

Once the selected dwelling has been located, and it has been confirmed that it is a family dwelling, that is, a surveyable dwelling, as a result of the first contact with the household, the following cases may occur:

- Household surveyed

This is considered to be the household that agrees to provide the information and from which the completed Household Questionnaire is obtained.

In each household, one Household Questionnaire must be completed, and if possible, the corresponding Disability and Limitation questionnaires, in accordance with the number of persons 6 years old and over or under 6 years of age, respectively, who have some disability or limitation, and the corresponding Main carer questionnaires, in accordance with the number of

persons who, having disabilities or limitations, receive assistance from another person.

- Household not surveyed

The household does not participate in the survey due to one of the following circumstances:

*Refusal:* This occurs when an entire household, or the person(s) that can complete the Household Questionnaire refuse(s) to participate in the survey.

This incidence may take place at the time of the first contact with the household, or after the first contact, when for some reason, the household refuses to facilitate the Household Questionnaire.

Nevertheless, those households that, without having refused to participate, do not provide, in the Household Questionnaire, the data corresponding to sections B (except column 6: date of birth), D and/or E (Disabilities and/or Limitations), are also considered to be refusals.

*Absence:* This incidence occurs when all of the members of the household are absent, and will continue to be so during the period of time in which the fieldwork in the section is to last.

*Inability to respond:* This incidence takes place when all of the members of the household are unable to respond to the household questionnaire, due to disability or illness, lack of knowledge of the language or some other circumstance.

- *Incidences concerning persons*

These may occur in persons who must complete the *Disability Questionnaire*, the *Limitation Questionnaire* and the *Main carer questionnaire*.

This type of incidence does not cause the household to be considered not surveyed. For a household to be considered surveyed, it is enough to have filled out the *Household Questionnaire* completely.

Incidents concerning persons occur when, due to any of the aforementioned causes in the households, that is, refusal, absence or inability to respond, the corresponding questionnaire is not completed.

Given that the last two are a reason for a proxy interview, they should only be considered an incidence covering persons when a *proxy* response is not obtained during the time that the work in the section *elapses*. The Disability and/or Limitation questionnaires may be answered by another person in only four exceptional cases. When it is the Main carer questionnaire, the information may be provided by another, well-informed person, in only three exceptional cases.

**Treatment of the incidences**

- *Incidences concerning dwellings*



Empty or unlocatable dwellings or dwellings intended for other purposes are replaced by other dwellings in the same section.

Unavailable or inaccessible dwellings may only be replaced if the cause of the inaccessibility disappears during the time in which the work in the municipality lasts.

In the case of the dwellings previously selected in another Population Survey, when this situation is detected before the fieldwork, the dwelling will be replaced by the first available valid reserve dwelling without having to be visited, assigning it the incidence of PS (previously selected).

In case the previous collaboration is not detected prior to the fieldwork, but rather, during the visit itself to the dwelling, there will be two possible treatments:

- If the human group that inhabits the dwelling accepts participating in the survey, the interview will be conducted normally, considering, in this case, that the dwelling is surveyable and the household is surveyed.
- If the human group does not accept participating, the dwelling is replaced by the first available valid reserve dwelling, assigned it the PS incidence.

*- Incidences concerning households*

Those households that have refused to participate are subject to replacement, following the same norms as in the case of incidences concerning dwellings.

Once this situation of absence has been checked, the dwelling should be replaced following the rules given in the section on incidents concerning dwellings.

If the household is unable to respond, there is also a case for replacement.

These treatments are applicable to both original dwellings and replacement dwellings. The number of replacement dwellings per section is 20.

*- Incidences concerning persons*

Incidents concerning persons, as they are not a reason for replacing the household, are accepted as such and receive no treatment at all.

## **Questionnaires**

*- Household Questionnaire*

The Household Questionnaire is a document designed for the purpose of recording those persons in the household who have some type of disability, as well as collecting information on socio-demographic characteristics of all of the members of the household, and of certain aspects regarding the surveyed household, with the household therefore being the observation unit.

The information collection method for this questionnaire is the personal interview, completed where necessary by means of a telephone interview.

As a general rule, the informant of the Household Questionnaire should be a person who is sufficiently informed, as s/he must provide different data on the members of the household. Given that the questionnaire requests information on all members of the household regarding fundamental socio-demographic variables, as a general rule, the informant should be the household reference person, or failing this, her/his spouse or partner, father or mother, brother/sister or son/daughter (depending on age), another relative or another member of the household not linked to the reference person by kinship bonds, in this last case, choosing that person who has resided the longest therein.

- *Disability Questionnaire (Persons 6 years old and over).*

The questionnaire is designed for the purpose of collecting information on the disabilities of the persons resident in the household aged 6 years old and over, the characteristics of these disabilities, the aid that they have requested, as well as other relevant data in the study of persons with disabilities.

A Disability Questionnaire is completed for each one of the persons aged 6 years old and over who have stated, in the Household Questionnaire, that they have some kind of disability.

The method of information collection is the personal interview for the target person of study. The person who should answer is the target person of the interview. However, the response of another person (spouse or partner, mother, father, son, daughter, carer, etc.) is admitted in the following cases: inability to respond due to illness, absence during the entire time in which the work in the section is carried out, or language difficulties. If the person is under 18 years of age, this questionnaire should be answered by the father, mother, guardian or another person in the household who is sufficiently informed.

- *Limitation Questionnaire (Persons 0 to 5 years of age).*

This questionnaire is designed for the purpose of collecting information similar to the former, in this case referring to the limitations of children under 6 years of age.

The information collection method is the personal interview of parents or guardians.

- *Main Carer Questionnaire*

This questionnaire is designed for the purpose of collecting information regarding the characteristics of the main carers. The goal is to obtain information on the demographic and social characteristics of carers, and

another series of data relevant to the study, regarding the situations of both persons with disabilities and carers.

A *Main carer* questionnaire is filled out for each of the persons who have stated that they have some type of disability (aged 6 years old and over) or some limitation (0 to 5 years of age) and who receive aid from another person.

The information collection method is the personal interview of the target person of study - the main carer - . In exceptional cases, the information may be collected by telephone.

The person who should answer is the target person of the interview. However, a response from another person who is sufficiently informed is admitted, in the following cases: long-term absence, night-time carer or language difficulties.

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## **7 Fundamental characteristics under study; disabilities, impairments and limitations**

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### 7.1 *Disability (persons aged 6 years old and over)*

For the purposes of the Survey, disability is understood to be any important limitation to carrying out everyday activities, that has lasted or is expected to last more than one year, and that is caused by an impairment. A person is considered to be disabled, even if the disability is overcome with the use of external technical assistance or with the assistance or supervision of another person.

The following disability categories are considered (the names of the disabilities listed below correspond to ICF language, whereas the wording used in the questionnaires is adapted to colloquial language, in such a way that it is comprehensible to any person):

- 1.- Vision
  - 1.1.- Perceiving any image
  - 1.2.- Detail visual tasks
  - 1.3.- Overall visual tasks
  - 1.4.- Other vision problems
  
- 2.- Hearing
  - 2.1.- Receiving any sound
  - 2.2.- Hearing loud sounds
  - 2.3.- Hearing speech
  
- 3.- Communication
  - 3.1.- Producing spoken messages

- 3.2.- Receiving spoken messages
  - 3.3.- Communication of written messages
  - 3.4.- Communication of messages through gestures, signs or symbols
  - 3.5.- Holding a conversation (only cognitive or intellectual problems)
  - 3.6.- Communication through devices and communication techniques
- 4.- Learning and application of knowledge and development of tasks(only problems of a cognitive or intellectual nature)
- 4.1.- Intentional use of the senses (watching, listening, etc.)
  - 4.2.- Basic learning (reading, writing, counting, etc.)
  - 4.3.- Undertaking simple tasks
  - 4.4.- Undertaking complex tasks
- 5.- Mobility
- 5.1.- Changing basic body postures
  - 5.2.- Maintaining the position of the body
  - 5.3.- Getting around inside the home
  - 5.4.- Getting around outside the home
  - 5.5.- Getting around via passenger transport
  - 5.6.- Driving vehicles
  - 5.7.- Picking up and carrying objects
  - 5.8.- Moving objects with the upper limbs
  - 5.9.- Fine hand use
- 6.- Self-care
- 6.1.- Washing oneself
  - 6.2.- Caring for body parts
  - 6.3.- Toileting related to urination
  - 6.4.- Toileting related to defecation
  - 6.5.- Toileting related to menstruation
  - 6.6.- Dressing and undressing
  - 6.7.- Eating and drinking
  - 6.8.- Looking after one's health: following medical prescriptions
  - 6.9.- Looking after one's health: avoiding dangerous situations
- 7.- Home life
- 7.1.- Acquisition of goods and services
  - 7.2.- Preparation of meals
  - 7.3.- Doing housework
- 8.- Interpersonal interactions and relationships
- 8.1.- Basic interpersonal interactions
  - 8.2.- Relating with strangers
  - 8.3.- Formal relationships
  - 8.4.- Informal social relationships
  - 8.5.- Family relationships

## 8.6.- Intimate relationships

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### 7.2- *Limitations (children under 6 years of age)*

In the group aged zero to five years old, the detailed study of disabilities is not used, given the difficulty of their detection. We have studied possible limitations that might have been detected in boys and girls this age. The following limitations have been considered:

1. Difficulty in remaining seated without aid (only for children 9 months old or over)
2. Difficulty in remaining standing without aid (only for children 15 months old or over)
3. Difficulty in walking alone (only for children 18 months old or over).
4. Total blindness
5. Severe difficulty in seeing
6. Total deafness
7. Severe difficulty in hearing
8. Difficulty in moving arms or weakness / stiffness in the arms
9. Weakness or stiffness in the legs
10. Seizures, the body becomes rigid or the person loses consciousness
11. Difficulty in doing things like other children her/his age
12. Frequently sad or depressed
13. In comparison with other children her/his age, s/he has difficulty in relating with other children (playing, expressing affection, etc.) or is frequently absent
14. Difficulty in understanding simple commands (only for children 2 years old or over)
15. Difficulty in recognising and naming at least one object (an animal, a toy, a cup, etc.) (only for children 2 or 3 years old).
16. Notices a difference in the way of speaking from other children her/his age (only for children 3, 4 or 5 years old).
17. Participates in an early learning programme or receives some kind of stimulation, speech-therapy service, etc.

18. A doctor (or psychologist) has diagnosed some other illness (or problem) with a total expected duration longer than one year, by which s/he needs special care or attention.

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### 7.3 *Impairments*

An **impairment** is understood to be any loss or anomaly of an organ, or of the function of that organ. For example, the absence of a hand, paraplegia, mental retardation, language disorders, etc.

#### IMPAIRMENT ASSIGNATION GUIDELINES:

There are certain assignment guidelines for the cases in which a disability may have been produced by different impairments, or when it is difficult for the informant to ascertain the true origin of her/his disability. These guidelines are described below:

I) When the disability is from an illness that has already been cured, or that is not evolving but has left some sort of after-effect, the impairment will be that of the organ, system or tract in which said after-effect has been produced. For example, a disability to hear, produced by a meningitis that has already been cured, is from an auditory impairment. Likewise, a disability to get around produced by a poliomyelitis that has already been cured, is due to an impairment in the lower limbs.

When the disability is the result of a degenerative and progressive illness, and therefore, one that has not been cured, the impairment considered will be that of the ill tract or system, independently of the after-effects that it is producing in another organ. For example, a disability to see caused by diabetes, is due to an endocrine-metabolic impairment, and a disability to get around caused by Parkinson's, is considered to be due to a nervous system impairment.

There is a third case, in which a disability may be produced by a long-term, but curable illness, such that, at the same time that the illness is directly affecting an organ, tract or system, the after-effects of said illness are already becoming evident. In general, these after-effects affect the same organ as the illness, and therefore, both paths lead to the same impairment. For example, the disability to get around produced by a pulmonary tuberculosis is due to a respiratory system impairment, in both the case of a person who has the disease and the case of a person who is already cured of it, and has pulmonary fibrosis as an after-effect.

IV) Aside from the previously explained methodological issues, two exceptions are established in the matter of the assignation of the impairment of origin, due to the growing demand for information that is arising from the differentiated study of these impairments:

- IV.1. Mental impairments (this includes headings 1.1, 1.2, 1.3, 1.4, 1.5, 1.6, 1.7 and 1.8 regarding mental retardation, dementia and other mental disorders).

This same section encompasses all mental disorders, independently of the type of illness that causes them (unchanging or in evolution) or the after-effects that they cause to other organs or systems.

For example, an unchanging illness such as Down's Syndrome or Autism is always considered to be a mental impairment, even in the case of having left after-effects on any other organ or system (for example, in the system of language, speech and voice).

IV.2. Nervous system impairments (this includes headings 6.1 to 6.6, regarding the paralysis of extremities, paraplegia, tetraplegia, disorders in the coordination of movements and/or muscle tone and other nervous system impairments). An exception is established in the application of guideline I (referring to unchanging illnesses): any Nervous System illness that generates, applying guideline I, an Osteoarticular Impairment, is classified as a Nervous System Impairment.

For example, a secondary medular section to a traffic accident, which would generate, on applying guideline I, an impairment of the lower extremities within the osteoarticular impairments, should be assigned the Paraplegia impairment as one of the Nervous System impairments.

In the cases in which the origin of the impairment is a degenerative illness that is in evolution (guideline II), such as the case of a paraplegia caused by amyotrophic lateral sclerosis, the inclusion in this heading of Nervous System Impairments does not imply any problem, as applying the general guidelines, one would reach the same conclusion.

V) When the disabilities involve the degenerative processes of several systems or tracts in which, either the age of the person has a determining influence or they are due to polymalformative syndromes of a congenital origin, the resulting original impairment of each disability, for each one if these two cases, is that which is known as Multiple Impairments.

These Multiple Impairments solely refer to persons with impairments caused by only two types of disorder:

V.1. Multiple Impairments of a congenital origin. This refers to persons with impairments that affect several organs and/or organic systems, and that are due to congenital polymalformations.

We can conclude from this definition that, if a congenital syndrome only affects one organ and/or system, the impairment assigned to it is that of the organ and/or system in which the after-effects have occurred.

This guideline has one exception, already states as Guideline IV.1 regarding Mental Impairments. That is, if these congenital syndromes produce mental disorders, the impairment assigned to the disability due to these mental disorders is Mental Impairments, and not Multiple Impairments.

For example, supposing the case of a person who, due to a congenital syndrome, has the following disabilities:

- No. 3 "Significant difficulty in seeing the face of someone on the other side of the street", caused by a deformation of the eyeball.
- No. 17 Significant difficulty in carry out complex tasks, caused by a moderate mental retardation.
- No. 21 Significant difficulty in walking or moving outside of the dwelling, caused by problems in the respiratory tract.

The Impairment of origin assigned to Disabilities 3 and 21 is 8.2 Multiple Impairments. Nevertheless, Disability 17 is assigned Impairment 1.3 Moderate mental retardation.

However, if the congenital syndrome had only generated a sight disability (3), it would be assigned Impairment 2.2 Poor vision, since it is a single organ or system that is affected.

V.2. Multiple Impairments due to degenerative processes derived from age. This includes persons who have several impairments in a not very serious state, mainly caused by their old age, by which each one of them, separately, would not be the direct cause of any disability, but the effect of all of them as a whole does cause disabilities. However, in the case that the surveyed person had arthrosis (even if it is a degenerative process due to age), this illness has its own entity, that is, by itself it produces a disability, and therefore, an Osteoarticular impairment corresponds to it.

### Examples of Disabilities and Impairments

The following shows several examples of disabilities with some of their possible causes, for the purpose of clarifying how the impairments should be assigned, since at times, different impairments can be attached to the same disability, depending on the illness that has caused it:

1. Significant difficulty in getting around using means of transport as a passenger (22). This disability may have been caused by:
  - Alzheimer's. It is assigned, applying guideline IV.1, to Disorders within the Mental Impairments.
  - Lack of a lower limb. It is assigned, applying guideline I, to Lower Extremities within the Osteoarticular Impairments.
  - Parkinson's Disease. It is assigned, applying guideline II, to Motor Coordination and/or Muscle Tone Disorders, within the Nervous System Impairments.
  - Tetraplegia due a cerebral paralysis. It is assigned, applying guideline IV.2, to Tetraplegia Impairment within the Nervous System Impairments.

Justification: Applying guideline I would lead us to an Osteoarticular Impairment. However, precisely guideline IV.2 establishes an exception in the cases in which an illness of the Nervous System causes an Osteoarticular Impairment, leading it



to Nervous System Impairments. Therefore, the disability is assigned to the Tetraplegia Impairment within the Nervous System Impairments.

- Mainly due to age. Even if the person does not have any illness that could affect her/him in a significant way in travelling on public transport, the set of health problems that affect her/him, mainly caused by old age, limit her/him in the carrying out of this activity. The disability is assigned, applying guideline V, to Multiple Impairments.

2. Blind or only distinguishes between light and darkness (1). This disability may have been caused by:

- Defects in the sight organs, for example, cataracts in both eyes. The disability is assigned, applying guideline II, to Total Blindness within the Visual Impairments.

- Severed Optic Nerve. The disability is assigned, applying guideline I, to Total Blindness within the Visual Impairments.

- Cerebral Tumour affecting cerebral vision centres. The disability is assigned, applying guideline II, to Other Nervous System Impairments within the Nervous System Impairments.

3. Significant difficulty in speaking comprehensively or saying sentences that make sense (8). This disability may have been caused by:

- Mental Disorders affecting the cerebral centre for language, speech and voice, for example, Autism. The disability is assigned, applying guideline IV.1, to Mental Impairments.

Justification: Even though this is an unchanging mental illness whose after affects have a repercussion on the System of Language, Speech and Voice, it is assigned a Mental Impairment, given that guideline IV.1 encompasses all of the mental disorders in Mental Impairments.

- Problems in the Vocal Apparatus, for example, absence of a jaw, laryngectomy, etc. These two illnesses are unchanging, and therefore, applying guideline I, the disability is assigned, in the first case, to Head Impairments within the Osteoarticular impairments, and in the second case, to Respiratory Apparatus Impairments within the Visceral Impairments.

- Degenerative Disorders affecting the Nervous System (except mental), for example, Parkinson's Disease or Cerebral Tumour. These two illnesses are degenerative, and therefore, applying guideline II, they are assigned to Nervous System Impairments. In the first case, it is assigned to the Impairment of Motor Coordination and/or Muscle Tone Disorders, and in the second case, to other Nervous System Impairments.

- Disorders that do not evolve affecting the Nervous System and that affect the cerebral language centre or nerves in the production of speech and voice (except mental), for example, Intercranial Injury, Cerebral Paralysis, Severed Medula. These illnesses are unchanging, and therefore, applying guideline I, the disability is assigned to the Impairments of Language, Speech and Voice.

## CLASSIFICATION OF IMPAIRMENTS:

The following categories of impairment are considered:

### *PERSONS AGED 6 YEARS OLD AND OVER:*

#### **1.- Mental impairments**

##### *1.1.- Developmental delay*

This refers to children up to the age of 14 years old, whose mental development is below normal. Due to their level of maturity, these children may display behavioural and learning problems.

##### *1.2.- Profound and severe intellectual impairment*

This refers to persons with an intelligence quotient between 0 and 34, with certain characteristics according to age, in: the areas of psychomotor and language development, in social and occupational abilities, in personal and social autonomy, in the educational and behavioural process. These persons are unable to care for themselves in feeding, excretion, hygiene, and dress, and constantly require the aid of a third person for assistance and protection.

##### *1.3.- Moderate intellectual impairment*

This refers to persons with an I.Q. between 35 and 49. These persons can learn social and occupational abilities, though they do not pass the second grade of Primary education or GBE. They can contribute to their own maintenance through protected workshops, under strict supervision.

##### *1.4.- Mild intellectual impairment*

This refers to persons with an I.Q. between 50 and 69. Adolescents can acquire practical abilities and academic knowledge up to the level of sixth grade of Primary education or GBE, though as of second or third grade, they need special support. Adults with a mild intellectual impairment develop social and communicative abilities similar to those of their unimpaired colleagues; many are not recognised as retarded outside of school or after finishing their education. They achieve a minimum level of autonomy and become integrated in special employment centres or in ordinary employment with support.

##### *1.5.- Borderline intelligence*

This refers to persons with an I.Q. between 70 and 85, with difficulties in adapting to the demands of the environment and to competitive environments. Up until adolescence, they present the same interests as the rest of the children their age, and afterwards, they present social adaptation problems. Adolescents can acquire practical abilities and academic knowledge until the level of sixth

grade of Primary education or GBE, and in secondary education, they require special support. Persons with borderline intelligence are capable of acquiring a minimum independence with their almost total social and/or labour abilities, though they require support occasionally. They do not usually have the legal recognition of disability (Disability Certificate).

#### *1.6.- Dementia*

This is a progressive loss of the cerebral functions that affects memory, and can also be accompanied by alterations in behaviour, learning and communication. It refers to all types of dementia, including Alzheimer's and those impairments that follow degenerative processes that eventually cause dementia, and on which the age of the person has a decisive influence.

#### *1.7.- Mental illness*

This refers to severe mental alterations with a duration longer than two years. Their consequences hamper or prevent the development of their functional abilities, in basic aspects of life, affecting the family, social and labour areas. These persons therefore require psychiatric and social attention. These include: schizophrenia and other schizoid disorders, paranoid-type disorders and affective disorders (maniacal disorder, bipolar disorder, chronic depression with/without psychotic symptoms).

#### *1.8.- Other mental and behavioural disorders*

This refers to persons with impairments of the general and specific mental functions, which have their origin in: Organic mental disorders (for example, an alcoholic psychosis), autistic-spectrum disorders, generalised development disorders, phobias, obsessions, somatic disorders, hypochondrias, mood disorders, anxiety disorders, adaptive and somatoform disorders, personality disorder, etc.

### **2.- Visual impairments**

This refers to persons with functional impairments of the visual organ and of the associated structures and functions, including the eyelids.

#### *2.1.- Total blindness*

This refers to persons who have no perception of light in either eye.

#### *2.2.- Poor eyesight*

This refers to persons with moderate (<0.3) or severe (<0.12) visual impairments, or with moderate (60° diameter or less) or severe (20° or less) impairments in their visual field.

### **3.- Hearing impairments**

This refers to persons with impairments of functions structures associated with the hearing apparatus.

### *3.1.- Prelocution deafness*

This refers to persons with deafness, which manifests itself prior to language acquisition (children). This includes deaf-muteness where muteness is a consequence of prelocution deafness.

### *3.2.- Postlocution deafness*

This refers to persons with deafness that manifests itself after language acquisition (adults), with total hearing loss, and who cannot benefit from the use of hearing aids.

### *3.3.- Hard of hearing*

This refers to persons with different degrees of hearing loss: moderate (45-50 dB), severe (71-91 dB), profound (>91 dB). They can benefit from the use of hearing aids.

### *3.4.- Balance disorders*

This refers to persons with labyrinthine vertigo (Meniere's disease being the most common type), dizziness and locomotion defects due to vestibular disorders.

## **4.- Language, speech and voice impairments**

This refers to persons with language comprehension and/or production impairments, speech production and/or articulation impairments, and voice disorders.

### *4.1.- Muteness (not through deafness)*

This refers to persons whose sound production organs are normal, but are mute as a result of brain damage to the speech centres, mental disorders, certain types of autism, etc.

### *4.2.- Difficult or incomprehensible speech*

This refers to persons with severe language after-effects, such as aphasia, dysphasia, dysarthria, dysphonia, dysphemia, etc., caused by injuries in the cerebral language region, for example, CVA (cerebral vascular accident), craneocerebral accident, language disorders associated with dementia, mental retardation, etc.

*CVA is the generic name given to a group of cerebral diseases of a vascular origin. These include brain haemorrhage, cerebral thrombosis and cerebral embolism.*

*Aphasia: Loss or impairment of the ability to express oneself through speech, writing or signs, or to understand written or spoken language, as a result of injury or illness affecting brain centres. There are many different types of*

*aphasia. Dysarthria: An imperfect articulation of speech, due to an impaired muscle control, caused by damage to the nervous system. Dysphonia: A deviance in voice intensity, tone and pitch. Dysphemia: Stuttering.*

## **5.- Osteoarticular impairments**

This refers to persons with mechanical and motor alterations of the face, head, neck and limbs, as well as the absence of limbs, resulting from damage to the support elements of the body (mainly the skeletal system).

### *5.1.- Head*

This refers to persons with structural defects, malformations and/or functional defects of the bones and articulations of the head and/or face (anomalies affecting the mouth, teeth, cleft lip, etc.).

### *5.2.- Spinal column*

This refers to persons with impairments due to congenital malformations (e.g. spina bifida), acquired deformities (kyphosis: an excessive backward curvature; Scoliosis: an excessive lateral curvature; Lordosis: an excessive curvature towards the front; Combinations thereof: kyphoscoliosis, lordoscoliosis, etc.); alterations of the vertebrae (intervertebral hernia, collapsed vertebrae due to osteoporosis, for example), after-effects of injuries, infections, rheumatism (osteoarthritis: a form of degenerative rheumatism caused by age, that involves no articular deformation; arthritis: a form of rheumatism consisting of the inflammation of the articulations with articular deformation, etc, ...).

### *5.3.- Upper limbs*

This refers to persons with congenital and/or acquired anomalies of the shoulder, arms, hands (absence thereof, defects affecting bone length or width), articular defects (ankylosis, function impairments, etc.).

### *5.4.- Lower limbs*

This refers to persons with congenital and/or acquired anomalies of the bones, articular defects, etc.; defects in the pelvis, the knees (varus ( ) or valgus X), ankles and feet (flat, hollow, varus, valgus, club, etc.).

## **6.- Nervous system impairments**

This refers to persons with severe anomalies in the structures and/or functions of their central and peripheral nervous systems (regardless of the cause: malformations, infections, tumours, etc.) affecting the musculoskeletal system and the articulations.

### *6.1.- Paralysis of an upper limb*

This refers to persons with a total loss of mobility of an upper limb (monoplegia). If the paralysis is partial or incomplete, the condition is called monoparesis.

### *6.2.- Paralysis of a lower limb*

This refers to persons with a total loss of mobility of a lower limb (monoplegia) or a partial or incomplete paralysis (monoparesis).

### *6.3.- Paraplegia*

This refers to persons with a total loss of mobility of both lower limbs, regardless of the cause (injury, infection, degeneration, tumour, etc.). Partial or incomplete loss (paraparesis) is also considered.

### *6.4.- Tetraplegia*

This refers to persons with a total loss of mobility of all four limbs. Partial loss (tetraparesis) is also considered

### *6.5.- Motor control and/or muscular tone disorders*

This refers to persons with impairments of the CNS (central nervous system), causing movement lack of coordination, involuntary movements, tremors, tics, stereotypy (persistent repetition of acts, movements, words or phrases linked to different conditions, particularly mental illness), balance alterations, non-labyrinthine vertigo (including essential vertigo, hysterical vertigo, vertigo caused by cerebral arteriosclerosis, diseases of the central nervous system, cardiopathy) and impairments due to an increase or decrease in muscle tone. Also included are disorders of the CNS, such as Parkinson's disease, cerebral palsy, epilepsy, multiple sclerosis, amyotrophic lateral sclerosis, etc.

### *6.6.- Other impairments of the nervous system*

This refers to persons with muscular dystrophy (degeneration of the muscle with progressive atrophy, without observable injury of the spinal cord), partial atrophy, hemiplegia, etc.

## **7.- Visceral impairments**

### *7.1.- Respiratory system*

This refers to persons with a severe impairment of their respiratory functions, with regard to their frequency, intensity, rhythm, presence of structural defects in some part of the respiratory tract, etc. It includes persons who depend on artificial devices to maintain their respiration, tracheotomised persons, etc.

### *7.2.- Cardiovascular system*

This refers to persons with severe impairments of their cardiac functions (frequency, rhythm, cardiac output volume, etc.), as well as the functions of the blood vessels (arterial system, venous system, capillary system, etc.). It also includes severe malformations of the heart, heart valves, etc. This group includes persons who are dependent on any device or apparatus acting on the heart or the valve system, to maintain their functions, such as artificial valves, pacemakers, transplants, etc.

### *7.3.- Digestive system*

This refers to persons with severe impairments in the functions and/or structures of the different sections of the digestive tract (mouth, tongue, oesophagus, intestine), causing difficulty in chewing, swallowing, digesting, etc. It also considers malformations, obstructions, severe disorders involving vomiting, diarrhoea, excessive weight loss, etc. , in addition to severe functional and/or structural disorders of the glands attached to the digestive tract, including the gall bladder, liver and pancreas, as well as any after-effects of surgery (stomas, fistulas, etc.).

#### *7.4.- Genitourinary system*

This refers to persons with severe impairments affecting the functions of the kidneys, ureters, bladder, urethra, sphincters, etc. (severe renal insufficiency, retention, urinary incontinence, etc.) and malformations of said organs, as well as the dependence on special devices such as catheters, artificial kidneys, etc. Regarding the genital system (internal, external, male or female), severe anatomical and/or functional defects are considered, including severe disorders in the fulfilment of the sexual functions, sterility, etc.

#### *7.5.- Endocrine-metabolic system*

This refers to persons with severe impairments due to disorders of the endocrine glands (dwarfism, gigantism, hyper/hypothyroidism, disorders of the adrenal glands, diabetes, obesity, etc.). Likewise, this includes severe impairments due to congenital metabolic errors (of proteins: Phenylketonuria, Tyrosinemia, etc.; of fats: Hypercholesterolemia, Lipid storage disorders, Hypertriglycerinemia, etc.; of sugars: Galactosemia, Fructose intolerance, etc.)

#### *7.6.- Haematopoietic system and immune system*

This refers to persons with severe impairments due to disorders of the haematopoietic organs (bone marrow, spleen, ganglia, etc.) and/or of the blood components (cells, plasma), alterations of coagulation and/or haemostasis (haemophilia). Regarding the immune system, severe disorders are considered, be they congenital or acquired (repeated infections, immune-based diseases, severe allergies, etc.)

### **8.- Other impairments**

#### *8.1.- Skin*

This refers to persons with severe impairments due to functional/structural skin disorders (regulation, moisture, temperature, pain, pigmentation, allergic reactions, itches, regeneration defects, etc.) and severe disorders of parts attached to the skin (nails, hair, glands)

#### *8.2.- Multiple impairments*

This refers to persons with impairments that affect several organs and/or organic systems, and that are due to congenital disorders. Among the former are congenital poly-malformations due to chromosomopathies, embriopathies

(rubella, toxoplasmosis), fetopathies (for example, cleft lip and palate and polydactylism), and any congenital or acquired poly-malformative syndrome

### *8.3.- Impairments not classified elsewhere*

#### *CHILDREN BETWEEN THE AGES OF 0 AND 5 YEARS OLD:*

##### **1.- Mental impairments**

###### *Developmental delay*

This refers to children up to the age of 14 years old, whose mental development is below normal. Due to their level of maturity, these children may display behavioural and learning problems

###### *Profound and severe intellectual impairment*

This refers to children with delays in the areas of psychomotor and language development, and in their educational and behavioural process (for example, children who at the age of 3 are unable to walk or speak, and are hardly able to communicate through gestures or articulated sounds. They only know their close relatives, do not respond to simple orders and have hardly developed any self-care habits).

###### *Moderate, mild or borderline intellectual impairment*

This refers to children with deficiencies in the areas of development described in the preceding paragraph (for example, speech deficiencies in children above the age of 3).

###### *Other mental and behavioural disorders*

This refers to children with autism, phobias, schizophrenia, neuroses, hyperactivity, etc.

##### **2.- Visual impairments**

This refers to children with functional impairments of the visual organ and of the associated structures and functions, including the eyelids

###### *Total blindness*

This refers to children with no perception of light in either eye

###### *Poor eyesight*

This refers to children with moderate (<0.3) or severe (<0.12) visual impairments, or with moderate (60° diameter or less) or severe (20° or less) impairments in their visual field

##### **3.- Hearing impairments**



This refers to children with impairments of function and associated hearing apparatus structures

#### *Prelocution deafness*

This refers to children with deafness that manifests itself prior to language acquisition. This includes deaf-muteness, where muteness is a consequence of prelocution deafness

#### *Postlocution deafness*

This refers to children with deafness that manifests itself after language acquisition, where loss of hearing is total. These children cannot benefit from the use of hearing aids

#### *Hard of hearing*

This refers to children with different levels of hearing loss: moderate (45-50 dB), severe (71-91 dB), profound (>91 dB). They can benefit from the use of hearing aids

#### *Balance disorders*

This refers to children with labyrinthine vertigo (Meniere's disease being the most common type), dizziness and locomotion defects due to vestibular disorders

### **4.- Language, speech and voice impairments**

This refers to children with language comprehension and/or production impairments, speech production and/or articulation, and voice disorders

#### *Muteness (not through deafness)*

This refers to children whose sound production organs are normal, but are mute as a result of brain damage to the speech centres, mental disorders, certain types of autism, etc.

#### *Difficult or incomprehensible speech*

This refers to persons with severe language after-effects, such as aphasia, dysphasia, dysarthria, dysphonia, dysphemia, etc., caused by injuries in the cerebral language region, for example, CVA (cerebral vascular accident), craneocerebral accident, language disorders associated with dementia, mental retardation, etc.

CVA is the generic name given to a group of cerebral diseases of a vascular origin. These include brain haemorrhage, cerebral thrombosis and cerebral embolism.

Aphasia: Loss or impairment of the ability to express oneself through speech, writing or signs, or to understand written or spoken language, as a result of disease or damage affecting brain centres. There are many different types of aphasia. Dysarthria: An imperfect articulation of speech due to an impaired

muscle control caused by damage to the nervous system. Dysphonia: A deviance in voice intensity, tone and pitch. Dysphemia: Stuttering

### **Osteoarticular impairments**

This refers to children with mechanical and motor alterations of the face, head, neck and limbs, as well as the absence of limbs, resulting from damage to the support elements of the body (principally the skeletal system)

#### **5.3.- Upper limbs**

This refers to children with congenital and/or acquired anomalies of the shoulder, arms, hands (absence thereof, defects affecting bone length or width), articular defects (ankylosis, function impairments, etc, ...)

#### **5.4.- Lower limbs**

This refers to children with congenital and/or acquired anomalies of the bones, articular defects, etc.; defects in the pelvis, the knees (varus ( ) or valgus X), ankles and feet (flat, hollow, varus, valgus, club, etc.).

#### **5.9.- Other osteoarticular impairments**

This refers to children with structural defects, malformations and/or functional defects of the bones and articulations of the head and/or face (anomalies affecting the mouth, teeth, cleft lip, etc.)

This refers to persons with impairments due to congenital malformations (e.g. spina bifida), acquired deformities (Kyphosis: an excessive backward curvature; Scoliosis: an excessive lateral curvature; Lordosis: an excessive curvature towards the front; Combinations thereof: kyphoscoliosis, lordoscoliosis, etc.); alterations of the vertebrae (intervertebral hernia, collapsed vertebrae due to osteoporosis, for example) after-effects of injuries, infections, rheumatism (osteoarthritis: a form of degenerative rheumatism caused by age, that involves no articular deformation; arthritis: a form of rheumatism consisting of the inflammation of the articulations with articular deformation, etc.).

### **6.- Nervous system impairments**

This refers to children with severe anomalies in the structures and/or functions of their central and peripheral nervous systems (regardless of the cause: malformation, infection, tumours, etc.) affecting the musculoskeletal system and the articulations.

#### ***Paralysis of an upper limb***

This refers to children with a total loss of mobility of an upper limb (monoplegia). If the paralysis is partial or incomplete, the condition is called monoparesis

#### ***Paralysis of a lower limb***

This refers to children with a total loss of mobility of a lower limb (monoplegia) or a partial or incomplete paralysis (monoparesis)

### *Paraplegia*

This refers to children with a total loss of mobility of both lower limbs, regardless of the cause (injury, infection, degeneration, tumour, etc.). Partial or incomplete loss (paraparesis) is also considered.

### *Tetraplegia*

This refers to children with a total loss of mobility of all four limbs. Partial loss (tetraparesis) is also considered.

### *Motor coordination and/or muscle tone disorders*

This refers to children with impairments of the CNS (central nervous system), causing movement lack of coordination, involuntary movements, tremors, tics, stereotypy (persistent repetition of acts, movements, words or phrases linked to different conditions, particularly mental illness), balance alterations, non-labyrinthine vertigo (including essential vertigo, hysterical vertigo, vertigo caused by cerebral arteriosclerosis, diseases of the central nervous system, cardiopathy) and impairments due to an increase or decrease in muscle tone. Also included are disorders of the CNS, such as cerebral palsy, epilepsy, multiple sclerosis, amyotrophic lateral sclerosis, etc.

## **7.- Visceral impairments**

### *Respiratory system*

This refers to children with a severe impairment of their respiratory functions, with regard to their frequency, intensity, rhythm, presence of structural defects in some part of the respiratory tract, etc.

### *Cardiovascular system*

This refers to children with severe impairments of their cardiac functions (frequency, rhythm, cardiac output volume, etc.), as well as the functions of the blood vessels (arterial system, venous system, capillary system, etc.). It also includes severe malformations of the heart, heart valves, etc. This group includes persons who are dependent on any device or apparatus acting on the heart or the valve system, to maintain their functions, such as artificial valves, pacemakers, transplants, etc.

### *Digestive system*

This refers to children with severe impairments in the functions and/or structures of the different sections of the digestive tract (mouth, tongue, oesophagus, intestine), causing difficulty in chewing, swallowing, digesting, etc. It also considers malformations, obstructions, severe disorders involving vomiting, diarrhoea, excessive weight loss, etc., in addition to severe functional and/or structural disorders of the glands attached to the digestive tract, including the gall bladder, liver and pancreas, as well as any after-effects of surgery (stomas, fistulas, etc.).

### *Genitourinary system*

This refers to children with serious impairments affecting the functions of the kidneys, ureters, bladder, urethra, sphincters, etc. (severe renal insufficiency, retention, urinary incontinence, etc.) and malformations of said organs, as well as the dependence on special devices such as catheters, artificial kidneys, etc.

Regarding the genital system (internal, external, male or female), severe anatomical defects are considered

### *Endocrine-metabolic system*

This refers to children with severe impairments due to disorders of the endocrine glands (dwarfism, gigantism, hyper/hypothyroidism, disorders of the adrenal glands, diabetes, obesity, etc.).

Likewise, this includes severe impairments due to congenital metabolic errors (of proteins: Phenylketonuria, Tyrosinemia, etc.; of fats: Hypercholesterolemia, Lipid storage disorders, Hypertriglycerinemia, etc.; of sugars: Galactosemia, Fructose intolerance, etc.)

### *Haematopoietic system and immune system*

This refers to children with severe impairments due to disorders of the haematopoietic organs (bone marrow, spleen, ganglia, etc.) and/or of the blood components (cells, plasma), alterations of coagulation and/or haemostasis (haemophilia). Regarding the immune system, severe disorders are considered, be they congenital or acquired (repeated infections, immune-based diseases, severe allergies, etc.)

## **8.- Other impairments**

This refers to children with severe impairments due to functional/structural skin disorders (regulation, moisture, temperature, pain, pigmentation, allergic reactions, itches, regeneration defects, etc.) and severe disorders of parts attached to the skin (nails, hair, glands)

### *Multiple impairments*

This refers to children with impairments that affect several organs and/or organic systems, and that are due to congenital disorders. It includes congenital poly-malformations due to chromosomopathies, embriopathies (rubella, toxoplasmosis), fetopathies (for example, cleft lip and palate and polydactylism), and any congenital poly-malformative syndrome

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## 7.4 *Characteristics related to disabilities and limitations*

### TECHNICAL AND PERSONAL ASSISTANCE AID

#### **Technical aid**

Technical aid is considered to be any product, instrument, equipment or technical system used by or intended for a person with disabilities, produced specifically for her/him or available for any other person, which compensates, relieves, neutralises the disability (hearing aids, external prostheses, wheelchairs, lifts or any elevating device, coverings with handle adaptations, illuminated magnifying glasses, tape recorders, computers, access ramps, guide dogs, etc.).

Different types of technical aid are detailed:

- Aid for therapy and training: antidecubitus aid.
- Aid for personal protection and care: protective aid carried on the body, aid for dressing and undressing, aid for toileting functions, urine channelling devices, urine collection systems, aid for washing, bathing and showering, aid for manicures and pedicures, aid for hair care, aid for dental care, aid for facial and skin care.
- Aid for personal mobility: external prostheses, aid for walking, used with an arm, aid for walking used with both arms, special cars, adaptations for cars, motorcycles and cycles, wheelchairs, accessories for wheelchairs, vehicles, transfer aid, aid for lifting and transport.
- Aid for housework: aid for preparing food and beverages, aid for doing the washing up, aid for eating and drinking, aid for cleaning the dwelling, aid for marking and maintaining textiles.
- Furniture and adaptations for dwellings and other buildings: tables, lighting devices, furniture for sitting, beds, aid for adjusting the height of furniture, support devices, opening/closing devices for doors and windows, construction elements in the home, devices for changing levels, security equipment for dwellings and other buildings, storage furniture.
- Aid for communication, information and signalling: technical aid for writing and manual drawing, for enabling reading, for hearing, sound transmission systems, for enabling signalling and/or pulsing, aid for communication (including face-to-face communication), typewriters and word processors, calculators, technical aid based on a computer, telephone communication, telephones and aid for telephoning, information systems (alarms, warnings and/or indicators), environment control, adapted toys.
- Aid for manipulating products and goods: aid for operating packaging, for helping/substituting hand and/or finger functions, for reaching at a distance, for fixing, for transport by body action and by wheels (for personal use)
- Aid for recreation: games.

#### **Personal assistance aid**

Personal assistance aid is considered to be any direct assistance offered by another person to a person with disabilities in order to carry out everyday activities.

The main personal assistance aid may be referred to as:

- Aid in personal care: dressing, bathing, eating or drinking, using the bathroom, etc.
- Aid in carrying out housework: cooking, washing, ironing, doing the grocery shopping, etc.
- Aid for strolling and getting around: old "guide" persons, for lifting and laying down, for pushing the chair, etc.
- Supervision aid for persons with severe mental problems or severe behavioural problems.
- Other aid: for making requests, sign language interpreter, etc.

Personal assistance should not be confused with professional support, such as, for example, psychotherapy, rehabilitation, education, etc. The latter, must be carried out by qualified personnel, and do not directly seek the performance of everyday activities.

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## SEVERITY

With this study, we obtain a broader qualitative perspective of the conditions of the population with disabilities. As expressed previously, the continuous decreasing trend of the mortality rates has caused not only an increase in life expectancy, but also an elevation in the impairment and disability rates that reflect a change in the mortality-morbidity relationship: a duality is observed between this increase in years lived and the quality of these extra years. Therefore, the issue is to ascertain the health conditions in which the surviving population with disabilities lives.

Likewise, it provides the information necessary for the calculation of indices such as the Life Expectancy Free from Disabilities, according to degrees of severity, as is proposed in the International Recommendations in terms of Disability, as well as in the Health Programmes of the WHO.

The severity of the disability refers to the degree of difficulty in carrying out each activity with aid (in the case that the person receives aid) or without aid.

@Without any difficulty

@With moderate difficulty

@With severe difficulty

@Cannot carry out the activity

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## AGE AT START OF THE DISABILITY

Actual age at the time at which the disability appeared.

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## 7.5 *Characteristics relating to impairments*

### PROBLEM THAT CAUSED THE IMPAIRMENT

The study of this variable is essential to preparing social policies aimed at the reduction of those impairments that can be prevented.

They are classified as:

#### **Congenital.**

This includes all those impairments that are due to genetic-type problems, such as Down's Syndrome, hydrocephaly, etc., and those that are produced during the gestational period as a result of pregnancy toxemias, pregnancy infections, chronic illness of the mother, RH factor, etc.

#### **Problems during childbirth.**

This includes all those impairments that are due to traumas that the baby was subjected to at the time of childbirth, such as the use of forceps or ventouse, prolonged childbirth, etc.

#### **Traffic accidents.**

This includes those impairments caused by traffic accidents. It also includes those traffic accidents occurring during commutes to/from work, even if they are considered by labour legislation as work-related accidents.

#### **Accident in the home.**

This includes those impairments caused by accident occurring within the home, or in the outside area that is the property of the estate.

#### **Recreational accident**

#### **Work-related accident.**

**This does not include as work-related accidents those occurring in traffic accidents, during commutes to and from work, though it does include those occurring while one is carrying out a task as a driver, delivery person, traveller, etc.**

#### **Another type of accident**

#### **Professional illness.**

**This concept is understood in a broad sense, without considering that which is set out in the labour legislation. This includes both those cases in which the**

**profession has been the cause of the impairment, and those cases in which it has caused an impairment to worsen.**

#### **Illness (non-work-related)**

##### **Other causes.**

This includes all those causes not mentioned in the above sections, such as iatrogenesis (alteration of the state of the patient caused by the doctor), food intoxications, etc.

It is important to indicate the fact that, in the group of persons over 64 years old, this heading has a special incidence, since it constitutes the origin of the Multiple Impairments due to degenerative processes derived from age.

#### **AGE AT START OF THE IMPAIRMENT**

Actual age at the time at which the disability appeared.

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## **8 Characteristics relating to persons with disabilities**

### **8.1 *Chronic illnesses***

This includes solely diagnosed illnesses. It does not include those that the subject believes or considers her/himself to have, and that do not have a medical certification.

The following illnesses are included:

- Spinal cord injury
- Parkinson's
- Lateral sclerosis
- Multiple sclerosis
- Agenesis / Amputation
- Laryngectomy
- Arthritis / Arthrosis
- Rheumatoid arthritis. Ankylosing spondylitis
- Muscular dystrophy
- Spina bifida / hydrocephaly
- Myocardial infarction. Ischaemic cardiopathy
- Cerebrovascular accidents
- Down's syndrome



- Autism and other disorders associated with autism
- Cerebral paralysis
- Acquired brain damage
- Senile Dementia of the Alzheimer Type
- Other types of dementia
- Schizophrenia
- Depression
- Bipolar disorder
- Pigmentary retinosis
- Myopia magna
- Senile macular degeneration
- Diabetic retinopathy
- Glaucoma
- Cataracts
- HIV/AIDS
- Rare illnesses
- Renal failure

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### 8.2 *Permanently bed-ridden*

The person must remain bed-ridden at all times, except very exceptional causes requiring her/his transfer, such as to the hospital or health centres.

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### 8.3 *Satisfaction with the technical aid*

This variable measures the degree of satisfaction with the technical aid received, or not received, by the person.

The following possibilities are considered:

- Yes.
- No, they are insufficient.
- I do not receive technical aid, even though I need it.

- I do not need technical aid.

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#### 8.4 *Birth range*

Birth range is defined as the number of pregnancies with more than 6 months of gestation (whether or not they reach the due date) that the mother of the person surveyed has had, not including the pregnancy leading to her/his birth.

In the case of identical or fraternal twins, that which is born first is the younger of the siblings.

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#### 8.5 *Belonging to non-governmental organisations*

This studies whether s/he belongs to any NGOs, and which the main impairment has been, and due to which s/he joined said Organisation, this information allowing for determining, on the one hand, the impairments with the highest degree of associationism and the best service infrastructure, and on the other hand, the advantages that remaining in these organisations implies for persons with disabilities, as compared with the rest of the persons with disabilities.

Belonging to an NGO, by a person with disabilities or her/his relatives, should be directly motivated by the disabilities of the person who at that time is filling out the Disability Questionnaire, and not by the disabilities of another person resident in the household (information which is collected in its respective questionnaire).

An NGO is considered to be those non-profit non-governmental organisations that are dedicated to the assistance, integration and development of those person with disabilities and whose partners are the persons with disabilities themselves and/or their relatives and friends.

Main non-governmental organisations of or for persons with disabilities:

- ALCER. federation National % of ASSOCIATIONS for Wrestling against diseases
- ASPACE. Spanish Federation of Associations for Assistance to Persons with Cerebral Paralysis
- ASPAYM. Federation of Associations of persons with spinal injuries and great physical disabilities
- COCEMFE. State Coordinating Confederation of Physically Disabled Persons in Spain
- FEAPS. Spanish Confederation of Organisations in support of Persons with Intellectual Disabilities
- FIAPAS. Spanish Confederation of Families of Deaf Persons

- ONCE. Spanish National Organisation for the Blind
- DOWN'S SYNDROME. Spanish Federation of Institutions for Down's Syndrome
- RED CROSS.
- FEDER. Spanish Federation of Rare Illnesses
- FEDACE. Spanish Federation for Brain Damage
- AECC. Spanish Cancer Association
- SPANISH ALZHEIMER'S FOUNDATION.
- FELEM. Spanish Federation for the Fight against Multiple Sclerosis
- SPANISH PARKINSON'S FEDERATION.
- Other NGOs for persons with disabilities

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#### 8.6 *Measurement of the use of the health and social services as a result of some disability*

This studies the use, by the person with disabilities, of the different socio-health services, analysing a series of factors, such as:

1. Services actually received: by type of service, number of days on which they have been received during the reference periods, and the economic scheme of the benefit.
2. Services needed but not received: by type of service that the reasons why the person could not access them.

The study of this variable has been focused for those health problems that cause disabilities.

This Section only includes those services whose origin is a disability, and not the results of other health problems. For example, a person may have a disability to use utensils and tools caused by an impairment of the upper limbs, and also have recently suffered a temporary limitation due to a sprained ankle, having required rehabilitation services and medical care for both problems. In this case, the Disability Questionnaire shall only include the services relating to the disability to use utensils and tools.

#### **Rehabilitation treatments finished**

This refers to treatments received prior to the last 14 days from the time of the interview that have already concluded, specifying the cause of this conclusion; whether it is because they have finished or because they have been interrupted indefinitely.

**Treatment ended.** A rehabilitation treatment is considered to be ended when all of the prescriptions made, in terms of the time and form of doing them, have

been fulfilled, according to an expert in the matter, regardless of whether the person may need to repeat them due to the disability or impairment continuing.

**Treatment interrupted.** This considers that a treatment has been indefinitely interrupted when not all of the prescriptions made by an expert on the rehabilitation treatment, and that should have been done during the indicated time, have been fulfilled, and the patient does not know if s/he is going to continue or not.

## TYPE OF SERVICE

### In the last 14 days:

- **Medical and/or nursing care** (except Chiropody Services). This considers those acts of health care for the treatment or monitoring of a given health problem, carried out by health professionals and received on an outpatient basis (including those appointments in hospitals), and those received in the home of the patient.

It includes minor outpatient surgery, which consists of small surgical interventions carried out on an outpatient basis in the hospital operating theatres with local or regional anaesthesia (removal of moles, small warts, ophthalmological laser surgery, etc.). It excludes rehabilitation and psychiatric care. It also excludes requests for prescriptions.

- **Diagnostic tests.** This considers those acts of health care for the diagnosis of a given health problem, carried out by health professionals and received on an outpatient basis (including appointments in hospitals).

- **Chiropody services.** This considers those acts of health care carried out by health personnel, for the treatment of foot afflictions. It includes that medical care received in the outpatient speciality offices of a hospital.

- **Medical-functional rehabilitation.** This considers those treatments aimed at avoiding a degenerative process, or at achieving the physical or sensorial recovery of the person. It includes physiotherapy, which consists of therapeutic methods using natural agents, such as water, heat or light, or mechanical measures, such as massages, exercise, etc. (kinesitherapy, hydrotherapy, thermotherapy, electrotherapy) and psychomotricity.

- **Language rehabilitation/speech therapy.** This considers all those therapeutic measures aimed at restoring the ability to communicate, to the greatest extent possible, in persons with language, speech and/or voice problems.

- **Orthotic and prosthetic rehabilitation.** This considers those measures that have the objective of applying therapies intended for achieving the physical recovery of persons with some health problem. It includes permanent and temporary orthopaedic prostheses and their renewal, special prostheses and orthotics. The latter are apparatus that partially or totally replace the lost functions of a limb that has not been amputated, and they are grouped under the generic names of

canes, crutches, orthopaedic chairs, apparatus for limbs, corsets, etc. This includes orthopaedic surgery.

- **Psychological assistance and/or mental health care.** This comprises those health actions, with or without hospitalisation, for the evaluation, treatment or monitoring of patients with mental illnesses, as well as the care for those psycho-social problems that accompany the loss of health in general.

- **Telephone assistance.** This considers the service intended for those persons who, for reasons of disability, old age, illness or social isolation, require continuous care, whether permanently or transitorily, by specialised personnel. This is a new technology resource, which applied to the telephone network, allows, by pressing a button, for contacting the central switchboard 24 hours a day and 365 days a year.

- **Programmed home care.** This considers that care that is carried out for patients who are chronically unable to visit a health centre.

- **Home help of a social nature.** This comprises social services, received at home, in assisting with household chores, paperwork, external laundry, meals delivered to the home, maintenance of the dwelling, surveillance and supervision in personal care and/or household chores, etc.

- **Day centre.** This is a centre that offers complete attention during the day (or night) for persons with serious or severe disabilities, or elderly persons in a dependency situation, with the objective of improving or maintaining the best possible level of personal independence and assistance to families or carers. This offers, among other things, the following services: consultancy, prevention, rehabilitation, orientation towards the promotion of independence, habilitation or on-site and personal care. It includes night centres.

- **Occupational centres:** This is a daytime service that provides a useful and therapeutic activity for persons with disabilities and needs for broad or generalised aid, who cannot access (temporarily or permanently) a normal or protected job post. It enables their personal adjustment, labour preparation and social integration.

- **Cultural, recreational, leisure and free-time activities:** This type of activity should be included only when it is carried out as a type of therapy intended to lessen the disability. Therefore, it does not include those cultural activities carried out in social centres for elderly persons.

In the last 12 months:

- **Occupational therapy and/or training in everyday activities (A.V.D.).**

**Occupational therapy.** The objective of this therapy is the development of a self-care activities (dress, eat, use the restroom, etc.), work and play activities to increase independence and prevent disability. Occupational therapy also provides advice regarding the convenience of technical aid, and shows how it is used.

**Training in everyday activities.** These are the activities aimed at learning everyday living habits, for persons with very severe disabilities (personal hygiene, dressing, etc.).

- **Information/Consultancy/Assessment.** This considers those services in terms of information and documentation of aid resources of the Community, regarding paperwork services and legal advisory, as well as regarding accessible communications systems (telephone, tv, etc.).

- **Health care provided by hospital personnel.** This refers to health care provided in hospitals. It includes both the care provided to patients admitted to hospital and to patients who are hospitalised who, without being admitted, have received care in the hospital (casualty services, observation, chemotherapy treatments, clinical explorations, etc.). It also includes home hospitalisation (home treatments for patients who have been treated in hospitals during the primary phase of the illness, and have returned home, though they require a direct control by hospital personnel: home dialysis, etc.).

It excludes outpatient appointments in hospitals, major and minor outpatient surgery, surgical interventions, orthopaedic surgery, psychiatric care and rehabilitation.

- **Psycho-social care for relatives.** This considers that service whose objective is to give psychological support to the relatives of the persons who have severe health problems.

- **Resting services (temporary stays).** These are residential services caring for the user during a given period of time. This services fulfil a dual function. On the one hand, they offer complete care to persons in a dependency situation (elderly persons or persons with disabilities); on the other hand, they serve as a break, by allowing the carers to enjoy rest or vacation periods.

- **Interpreting or sign language service.** This is a support service for deaf persons, in their ease and relationship with hearing persons, which aids in communication. The care may be:

- Individual and/or family, in relevant matters regarding health, housing, employment, social services, etc.

- Group and community (courses, days, conferences, etc.)

- **Other alternative communication systems.** These are systems and improve or replace the communication abilities of persons who cannot use, through the spoken and/or written language, through the use of methods and devices adapted to each person. For example:

- Braille method.

- Bliss language symbols.

- Tactile communication for deaf - blind persons.

- Communication via pictograms or simplified drawings.

- Morse method.

- **Health and/or adapted transport.** This considers the special transport of patients or persons who have had accidents, when according to the judgment of the medical staff, there is a situation of urgency or physical impossibility of the interested party.

- **Residential centres.** These are establishments intended to serve as a permanent and common dwelling, in which complete and continuous care is provided to the users thereof.

- **Tourism and spas for persons with disabilities.** This is a service intended to development leisure activities and the promotion of health, through trips for holidays and thermal treatments (spas).

The objectives of these programs include persons with mental, physical or sensorial disabilities being able to enjoy leisure and health goods in an adapted environment, in addition to favouring the rest of relatives and carers.

- **Orientation/labour preparation.** These are all of the services, intended for persons with disabilities seeking employment, which offer information and advice, and prepare a labour market insertion programme that is appropriate to the aptitudes of each person. The programme must include pre-labour training, aid in the job search, job bank service, training in specific tasks and monitoring, among other services.

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#### ECONOMIC PLAN OF SERVICES RECEIVED

- **Free of charge.** Those services that are received without having to pay their cost, or those that are paid by the patient her/himself with the right to the total return of the payment made by the Public System.

- **Direct payment.** This includes those services provided, which are paid by the patient her/himself without the right to the total or partial return of the payment made by the Public System. Likewise, this includes the medical contract and those other forms of payment through periodical quotas of private insurance that allow for using some type of health care.

- **Mixed payment.** This includes those services provided that are partially paid by the Public System.

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#### REASON WHY S/HE HAS NOT RECEIVED THE SERVICES S/HE NEEDS

- Waiting list
- Not available in the environment
- They cannot pay for it
- They do not fulfil at least one of the requirements
- Other reasons

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### 8.7 *Economic or tax benefits as a result of some disability*

This considers the economic benefits of a social nature aimed personally at the interviewee as a result of some disability.

c) Also included are the benefits obtained through the company in which the person works, and the amounts obtained as a result of insurance taken out directly by the patient.

The period of time for the receipt of these monetary and tax benefits is the last 12 months.

**PERIODIC BENEFITS** (defined in section 11. Classification characteristics regarding the home)

- Contributory pensions due to disability (permanent disability, passive types, SOVI, etc.)
- Non-contributory pensions as a result of the disability
- Allowances due to having a dependent child with disabilities
- Life and disability insurance. These are the amounts received as a result of the insurance taken out

**Illness.** This must be understood in the strict sense of a more or less severe alteration of health that affects, in general, the physical or mental integrity of individuals. Illness benefits include those benefits intended to compensate, either totally or partially, for the loss of a professional activity caused by an illness.

**Disability.** This must be understood as the lack of ability to carry out an activity of a prescribed degree, or to carry out a normal social life, when this lack of ability is permanent or remains longer than a limited period of time. This can be congenital or caused by an illness (except a professional illness) or an accident (except a job-related accident). Disability benefits include pensions, allowances and other cash benefits granted to invalids and persons with disabilities as a result of their situation.

- Other regular income due to disability

**NON-PERIODIC BENEFITS**

- Public aid for rehabilitation or specialised care
- Public aid for education
- Public aid for relative carers
- Public aid for enabling personal independence (technical aid and for accessibility and adaptation in the home)



- Public or private aid in the work area (social action aid)
- Other public aid
- Aid from other entities (NGOs, foundations, professional bodies, etc.)

#### COMPENSATION

- Compensation due to physical injury
- Compensation due to civil or criminal responsibility

#### TAX BENEFITS

- TAX BENEFITS in personal income taxes (by contributor with disabilities or by care to a parent or descendent of a person with disabilities)
- Registration tax (tax exemption for the 1st registration, VAT reduction)
- Tax on mechanised vehicles (road tax)
- Inheritance tax
- Other tax benefits (protected capital gains, right to assessment fees, etc.)

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### 8.8 *Changes in the relationship with economic activity and/or occupation, as a result of some disability*

When a person has made more than one change in her/his economic activity, or in her/his occupation, as a result of her/his disability or disabilities, the information refers solely to the first change made.

This considers three options that are excluded:

- a) They only changed their relationship with economic activity. This includes the changes between unemployed and inactive (or vice-versa) and also between the different inactivity situations (for example, a person who was dedicated to Housework, and due to the disability, changed to Another situation). It is necessary to emphasize that this option does not include those persons who have been employed in any of the two moments studied; before the appearance of the disability and after the appearance of the disability.
  - b) They only changed their profession or occupation. This refers to those changes of occupation due to the disability. This option only includes the persons who have been employed in the two moments studied.
  - c) They changed their relationship with economic activity and their occupation. This includes those changes from employed to unemployed or inactive situations (and vice-versa). This last option includes those persons who have been employed in only one of the two moments studied.
-

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8.9 *Relationship with economic activity before and after the first change made as a result of some disability*

This studies the effects of disability on a social level, that is, in which way a disability can limit, or not, the labour activity of the person, whether because it truly incapacitates her/him to work or because the work centres are not adequate for these persons (accessibility obstacles, social obstacles, etc.)

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8.10 *Employment before and after the first change made as a result of some disability*

The information obtained regarding this variable is very useful, as it provides data on the flows between the different occupations, due to disabilities, and enables reflecting on whether there is some group of occupations with a greater degree of attraction for persons in this group, who without stopping working, have been obligated to change labour tasks.

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8.11 *Type of working day*

This is classified as:

- Split shift
- Continuous morning working day
- Continuous afternoon working day
- Continuous night working day
- Reduced working day
- Shifts
- Irregular or variable working day, depending on the day
- Another type

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8.12 *Special Employment Centre*

These are the centres whose main objective is to carry out a productive work, participating regularly in market operations, and with the purpose of ensuring a remunerated job and the provision of personal and social adjustment services that their workers with disabilities require; at the same time, they intend to be an integration measure of the greatest number of persons with disabilities into the normal working scheme. The staff of the Special Employment Centres shall be comprised of the greatest number of workers with disabilities that the nature of the productive process allows, and in any case, of 70% of said staff.

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### 8.13 *Wage-earning workers of the company where s/he works*

This is classified as:

- Fewer than 10
- 10 to 19
- 20 to 49
- 50 to 99
- 100 or more

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### 8.14 *Employment Encouragement Measures for persons with disabilities*

This refers to the group of regulations aimed at the creation and maintenance of job posts, through the establishment of hiring aids for certain groups, enabling access to work for others, aiding in the establishment as self-employed workers or in the access to cooperatives, etc.

- By reservation quota for persons with disabilities in the public sector

Law 23/1988, of 28 July, Modifying the Law of Measures for the Reform of the Function of 2 August 1984, provides the innovation of extending the reservation quota of functionary posts, while improving the definition of the procedure for reaching it. This is all contained in the nineteenth additional provision of Law: *In public employment vacancies, a quota of no less than 3% of vacancies shall be reserved to be covered by persons with disabilities of a degree greater than or equal to 33%, until they progressively reach 2% of the total employees of the State Administration, so long as they pass the selective examinations and that, at the time, they provide the indicated degree of disability and compatibility with the performance of the corresponding tasks and functions, as is determined by law (article 19).*

- By reservation quota for persons with disabilities in the public private sector

The legislation in force regarding the reservation of job posts, which establishes that, for companies with fifty or more workers, the obligation of hiring a minimum of two percent of workers with disabilities.

As an alternative means of complying with that legal obligation, one must proceed to the creation of a Special Fund for the Employment of Persons with Disabilities, which would be funded, among other sources, by compulsory funds

of the companies that do not reach the legally established percentage of the reservation of job posts.

- Specific contract for persons with disabilities

This is a hiring modality for workers with disabilities with a degree greater than or equal to 33%, recognised as such by the authorised Organisation. The access, characteristics and duration of the contract vary, depending on the specific modality of the contract, which may be one of the following types:

- Permanent or indefinite employment contract for the hiring of persons with disabilities
- Permanent or indefinite employment contract for persons with disabilities coming from labour enclaves
- Temporary employment contract
- Employment contract for training
- Internship contract
- Temporary employment contract to substitute for the temporary incapacitation of person with disabilities
- Temporary employment contract conversion to permanent, for persons with disabilities who work in the Special Employment Centres
- Communication of conversion of temporary employment contract to permanent for persons with disabilities
- Employment contract regulating the labour relationship of a special nature for persons with disabilities working in Special Employment Centres
- Incentives for hiring, bonuses in Social Security quotas

The subsidies, bonuses of the business quotas for Social Security and tax deductions aimed at encouraging the hiring of workers with disabilities in ordinary companies, and the re-adaptation and accessibility of the job post, establishing a periodicity for the updates.

- Others (work labour, jobs with support, etc.)

**Labour enclaves:**

A labour enclave is understood to be that contract between an ordinary job market company, called the collaborating company, and a special employment centre, for the performance of jobs or services that are directly related to the normal activity of the company, and for whose performance, a group of workers with disabilities from the special employment centre is temporarily transferred to the work centre of the collaborating company. These are regulated, as a measure for encouraging the employment of persons with disabilities, by Royal Decree 290/2004, of 20 February.

**Employment with support:**

Employment with support is understood to be the group of orientation and individualised accompaniment actions in the job post, provided by specialised labour preparers, with the objective of facilitating the social and labour adaptation of workers with disabilities with special labour insertion difficulties in ordinary job market companies, in conditions that are similar to the rest of the workers who carry out equivalent posts (ROYAL DECREE 870/2007, of 2 July, regulating the programme of employment with support as a measure for the encouragement of the employment of persons with disabilities in the ordinary job market).

The actions for employment with support shall be developed within the framework of projects for employment with support, where the following actions, at least, must be considered:

- a) Orientation, advisory and accompanying the person with disabilities, preparing, for each worker, a programme for adapting to the job post.
- b) Work in bringing together and encouraging mutual aid between the worker who is the beneficiary of the programme of employment with support, the employer and the company staff that shares tasks with the worker with disabilities.
- c) Support for the worker in the development of social and community abilities, in such a way that s/he is able to relate to the labour environment in the best possible conditions.
- d) Specific training of the worker with disabilities in the tasks that are inherent to the job post.
- e) Monitoring of the worker and assessment of the insertion process in the job post. These actions have the purpose of detecting needs and preventing possible obstacles, both for the worker and for the company hiring her/him, that endanger the objective of insertion and permanence in the job.
- f) Advice and information for the company regarding the need and processes for adaptation to the job post.

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#### 8.15 *Form of knowledge of the job post*

This is collected as having knowledge of her/his current job post, or of the last one s/he had. It is classified as:

- Via a public employment service (INEM)
- S/he addressed the company directly
- The company got in touch with her/him
- Via employment websites
- Through a friend or relative

- Via a specialised Labour Insertion service
- Via an institution or association for persons with disabilities
- Another way

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#### 8.16 *Type of contract in her/his employment*

##### **Civil servant; permanent**

This type of contract is classified in the category of a contract with an indefinite duration, regardless of whether it is carried out continuously or sporadically. This are contracts that do not end so long as they are not cancelled, that is, so long as a dismissal interrupting them does not take place. The condition of a civil servant, even if it does not carry a labour contract, can be considered similar to an indefinite duration contract.

##### **Temporary (learning, internship or training, temp., service, seasonal or substitute)**

This type of contract is classified in the category of temporary contracts, which are contracts drawn up for a specific period of time, that is, when the end of the contract is determined by objective conditions, such as the expiry of a given period of time, the performance of a specific task, the re-incorporation of an employee who had been temporarily replaced, the performance of an internship or training period and the end of the substitutions of a part of work not carried out by those who are partially retired.

##### **Verbal agreement or without a contract**

This refers to the case in which there is no formal, signed contract, even if the work is not occasional, and even if it is regular or long-term

##### **Another type of contract**

Registered under this heading will be the free workers who can work for several employers in different labour agreements, and may be at the border between wage-earner and independent worker.

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#### 8.17 *Duration of the contract*

This includes the duration of the current contract, or rather, the duration of the last contract. It is classified as:

- Less than 6 months
- 6 months to 1 year
- From more than 1 year to 3 years

- 3 years and longer
- Without indefinite duration

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#### 8.18 *Time working*

This shows how much time the person has worked in her/his current employment. It is classified as:

- Less than 1 year
- 1 to 2 years
- 2 to 4 years
- More than 4 years

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#### 8.19 *Reason for stopping working*

This collects, for those persons who have worked at some point in time and are not currently working, the reason why they stopped working. It is classified as:

- The person reached the age of retirement
- Health reasons
- Early retirement or forced early retirement
- Voluntary early retirement
- Early retirement as a result of disability
- Work could not be reconciled with family responsibilities
- The desire to dedicate oneself solely to family
- The person became unemployed after the contract ended
- The person was made redundant
- The person's own free will
- Other reasons

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#### 8.20 *Time without employment*

This is considered, for those persons who have worked at some point in time, and are not currently working, the amount of time they have been unemployed. It is classified as:

- Less than 3 months
- 3 to 6 months
- 6 months to one year
- One to two years
- Two to five years
- More than five years

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### 8.21 *Job search*

This refers to person 16 years old and over with disabilities, and who are seeking employment, whether they are employed and seeking another job or they are unemployed.

#### METHOD USED IN LOOKING FOR WORK

This covers the three main actions in the job search, which are classified in:

- Was registered in a public employment office
- Was registered in a private employment office
- Has approached companies
- Has used personal contacts
- Through the press
- Has made efforts to set him or herself up on his/her own (land search, administration of licenses, etc.)
- Preparing for or taking public exams
- They are waiting on the results of previous applications
- They are waiting for a call from a public employment office
- Other methods
- They have not used any method

#### MAIN REASON FOR NOT FINDING EMPLOYMENT OR ANOTHER TYPE OF EMPLOYMENT

Among the reasons listed, the fundamental reason why the person believes that s/he is not finding employment, or another type of employment that adapts more to her/his intentions.

- Due to having a disability
- Due to not having experience



- Insufficient or inadequate studies
- Finding work is difficult for everyone
- Due to not having studies
- Other reasons

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### 8.22 *Reasons for not seeking employment*

For persons 16 years old and over who have not been seeking employment or working, the three main reasons for this situation are studied.

- The person has disabilities and believes it would be difficult to find employment
- They cannot work
- They believe that they will not find work, not ever having sought it before
- They believe that they will not find work, having sought it before
- They do not believe that there will be any work available
- They are affected by an employment regulation process
- They do not know where to look to find work
- They are waiting for a season with more activity
- They are waiting on the results of previous applications
- They are waiting to begin their freelance activity again
- Due to family or personal reasons
- Due to currently studying or receiving training
- Due to receiving economic benefits
- Due to being retired
- They do not need to work
- Other causes

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### 8.23 *Level of studies in progress. Persons 16 years of age and over*

#### CURRENT REGULATED STUDIES

Generally regulated studies are deemed to be those belonging to the official education system or which enjoy official recognition (by the Ministry of Education or Universities), with the requirements for enrolling, duration of study

and programmes officially regulated, such that the qualification is attained with a stable and basically common curriculum for all types of centres delivering those study programmes.

They are classified as:

- Specific special education
- Obligatory secondary education
- Social Guarantee Programme
- Intermediate cycles of professional training and the equivalent
- Post-Secondary Education
- Advanced cycles of professional training and the equivalent
- University education
- None of the above

**Special education:** Although the schooling of persons with disabilities should be carried out, by legal principle, in Ordinary Education Centres, there are exceptional special education modalities, when as a result of the psycho-educational evaluation, it is considered that, throughout her/his schooling, the student will require significant curricular adaptations in practically all areas of the curriculum, and when necessary, in addition, that in this centres, her/his adaptation and social integration will be reduced. As a general rule, two modalities can occur:

- Schooling in a Special Education Centre: in which all of the students have Special Educational Needs.
- Schooling in an Ordinary Centre, but in a Specific Classroom: in this case, students with disabilities attend the same Educational Centre as other students without disabilities, but their schooling is carried out in a Special Classroom within the Centre.

#### NON-REGULATED CURRENT STUDIES

- Occupational Vocational Training courses
- Other non-regulated studies lasting more than six months
- Other non-regulated studies lasting six months or less

**Course in Occupational Vocational Training.** Occupational Vocational Training (OVT) is aimed at persons with special difficulties in accessing the labour market, young persons, unemployed persons or those who need to improve or adapt their professional performance. They may be taught by public entities (Public Employment Services, Educational Centres) or private collaborators (companies, associations).

This item includes training activities related to:

\* Vocational Training and Insertion (VTI). The VTI Plan is comprised of actions aimed at unemployed workers, to provide them with qualifications that are ideal for their labour insertion.

\* Ongoing Training. This addresses employed workers, and its purpose is the improvement of competencies, qualifications and professional re-qualification.

\* Professional Recovery. Aimed at the rehabilitation, for employment, of persons of a working age afflicted by disabilities.

#### HIGHER LEVEL STUDIES COMPLETED

Additional information is obtained regarding the level of studies completed of the highest level, for persons 16 years old or over with disabilities.

This requests, for persons whose level of completed studies corresponds to university studies or the equivalent or advanced professional education, for their diploma, degree or branch. In a similar way, for all of the interviewees, they are asked if they have undertaken OVT, specifying which they have found useful in seeking employment.

Classification of branches, diplomas, degrees and OVT studies appears in Card 5 of the Annex.

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#### 8.24 *School integration and level of studies in progress. Persons 6 to 15 years of age*

##### LEVEL OF STUDIES IN PROGRESS

These may be classified in any of the following categories:

##### • **Unschoolled**

@Has never attended a School Centre due to her/his disability or disabilities

@Has stopped attended due to her/his disability or disabilities

@Has never attended or does not attend because there is no Centre in her/his area that adequately meets her/his needs

##### • **Schooled in a Special Education centre or classroom**

@In Special Education Centres studying obligatory basic or primary education

@In Special Education Classrooms studying obligatory primary or secondary education

@In Combined Education (Special and Ordinary) studying obligatory primary or secondary education

##### • **Schooled in an ordinary centre, integrated and receiving special aid**

@In Infants Education Centres

@In Primary education

@In Obligatory secondary education

• **Schooled in an ordinary centre, without any type of personalised aid**

@Primary education

@Obligatory secondary education

#### TYPE OF CENTRE ATTENDED

- Public centre. Educational system centre that is totally financed with public funds.
- Subsidised private centre. Educational system centre that is privately owned, but has public subsidies for the levels of obligatory education (Primary education and Obligatory secondary education, First cycle).
- Non-subsidised private centre. Educational system centre that is privately owned, with no type of public subsidy for the levels of obligatory education.

#### SCHOOL ABSENTEEISM DUE TO DISABILITIES

This is defined by means of the sum of all of the days in which absenteeism has occurred, that is, the child has not gone to school, throughout the latest academic year, even if this has occurred during different periods, and so long as these absences can be attributed to her/his disability or disabilities (for example, a disability to walk) and not to a common illness (such as: the flu, tonsillitis, etc.),

The following intervals are considered:

@Unschoolled

@Less than one week

@One or more weeks, but less than a month

@Between one and three months

@Between three and six months

@Six months or more

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#### 8.25 *Discrimination*

This includes, for persons with disabilities, the frequency with which they have felt discriminated as a result of their disabilities, they have not been allowed to do something, they have been bothered or made to feel inferior by another person. For persons who have felt discriminated, this includes whether they have

pressed charges and the situation in which this has taken place. The situations are:

- In health care
- In specialised support services (associations, early treatment. ...)
- In the school area or in training activities
- In seeking employment
- In the workplace
- In transport and commutes
- In the Public Administration
- In deciding on their wealth
- In hiring insurance
- In participating in cultural, recreational and leisure activities: museums, concerts, theatre, bars, discoteques, cinemas, tourism, etc.
- In social participation
- In social relations
- In another situation

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## 8.26 *Social networks and contacts*

### SOCIAL CONTACTS

This includes, for persons with disabilities, the place of residence and the frequency with which they see or use telephone or postal contact with a series of relatives and/or friends. These include:

- A parent
- A son/daughter
- A sibling
- A grandchild
- A parent-in-law
- Another relative
- A friend, not a neighbour

This also includes, for persons with disabilities, whether they have had the opportunity, in the last twelve months, to address or talk to persons they do not know, to relate to friends or close persons and to make new friends.

## ACTIVITIES THAT THEY CARRY OUT OR CANNOT CARRY OUT

There is a list of activities on which they mainly spend their free time and those which they would like to participate in but cannot, due to their disability or disabilities. These activities are:

- Watch TV or DVDs
- Listening to the radio or to music
- Read
- Talk on the telephone with relatives or friends
- Practice physical exercise (sports, strolls, etc.)
- Surf the Internet
- Chat or send emails
- Attend classes or courses
- Do hobbies, craftwork, handicrafts
- Visit relatives or friends
- Go shopping
- Attend sporting or cultural events
- Travel
- Visit libraries or museums
- Other

## CHANGE OF RESIDENCE

For all those persons with disabilities resident in the household, and who have changed residence as a result of their disabilities, this studies the main reason for the change.

This variable is classified into:

- Staying in a group establishment for a period longer than 6 months
- Better availability of health and/or social resources
- Environmental reasons
- To receive family attention
- Due to obstacles on entering and leaving home
- Due to obstacles within the home
- Other reasons
- In another situation

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## 8.27 *Accessibility*

This includes, for persons with disabilities, whether they have any difficulty in getting around normally in a series of places. These places are:

### THEIR DWELLING OR BUILDING

- In the entrance to their home
- In the lift
- On the stairs
- In the bathroom
- In the kitchen
- In other rooms of the dwelling
- In the terrace or patios
- In other places in their dwelling or building (garage, storage areas, etc.)

### PUBLIC TRANSPORT

- In accessing stations, stops, platforms, interchanges
- In arriving at the vehicle
- In getting into or out of the vehicle
- In getting into the seat
- In paying for or making use of the transport pass (ticket, bus pass, etc.)
- In finding their bearing in stations, airports and ports
- In reading, interpreting or understanding maps and signals
- In deciding the itinerary (choosing transfers, getting off at the appropriate stop, etc.)
- Other problems

### PRIVATE TRANSPORT

- In arriving at the vehicle
- In getting into or out of the vehicle, or accessing the seat

### ON THE STREET

- In going up to or down from the sidewalk
- In crossing the street

- In overcoming obstacles on the pavement (wastepaper baskets, streetlights, bollards, narrow sidewalks, etc.) or problems on the pavement (slippery ground, potholes, etc.)
- In identifying streets, intersections and signals
- Other problems

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## 8.28 *Health*

### SELF-EVALUATION OF STATE OF HEALTH

This includes the subjective perception, on the part of the individual interviewed, of her/his state of health in general. For example, a person may be blind, but consider her/his health to be very good in general.

This is classified on five levels:

@Very good

@Good

@Fair

@Poor

@Very poor

### CHRONIC ILLNESSES

A chronic illness is a long-term complaint that is not due to acute isolated processes.

This only considers those illnesses that have been diagnosed by health professionals. It therefore does not consider those that the subject believes or is convinced that s/he has, but that s/he does not have medical confirmation of.

It considers the following chronic illnesses:

@Asthma, chronic bronchitis or emphysema (including allergic asthma)

@Myocardial infarction or another heart disease

@Hypertension

@High cholesterol

@Cerebrovascular accident

@Arthrosis, arthritis or rheumatic problems

@Chronic cervical or lumbar back pain

@Diabetes



- @Allergy (except allergic asthma)
- @Stomach ulcer
- @Cirrosis or another hepatic illness
- @Cancer
- @Migraines or frequent headaches
- @Urinary incontinence
- @Chronic anxiety
- @Chronic depression
- @Another mental illness
- @Permanent injury caused by an accident
- @Another chronic illness

#### ACCIDENT RATE

An accident is defined as that fortuitous event that causes identifiable corporal damage.

This studies the environment in which the accident occurs

- @At home, stairs, foyer, etc.
- @In the street or road and it was a traffic accident
- @In the street, but it was not a traffic accident
- @At work
- @In the place of study
- @In a sports complex
- @In a recreational or leisure area
- @At another place

#### ANTHROPOMETRIC FEATURES

Weight is studied in kilograms and height in centimetres.

If the interviewed person is pregnant, her weight prior to the beginning of the pregnancy is recorded.

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#### 8.29 *Personal care*

This feature is included for all those persons who have, for any of their disabilities, stated that they receive personal aid.

It studies which persons dedicate personal care, that is, all of the persons who provide care to the person. It asks which of these persons is mainly dedicated to this care.

#### KINSHIP RELATIONSHIP BETWEEN THE PERSON WITH DISABILITIES AND THE PERSON RESPONSIBLE FOR THEIR CARE

It is specified if the person in charge of their care is:

@A member of the household, or a person who resides in the household without being a member thereof (employees of the household and established guests). The carer is identified by her/his number in order

@Does not reside in the household (in which case the existing relationship is indicated)

- Daughter/s
- Son/s
- Mother
- Father
- Spouse or partner
- Sister/s
- Brother/s
- Grandmother/s
- Grandfather/s
- Granddaughter/s
- Grandson/s
- Daughter-in-law/s
- Son-in-law/s
- Other relationships
- Non-resident employees who are professional social or health professionals
- Other domestic staff
- Friends or neighbours
- Public Administration social services. This includes that personal care provided by institutions belonging to the Public Administrations (IMSERSO, Social Affairs Councils of Autonomous Communities, etc.)
- Social services of non-public institutions (NGOs, associations). This includes that personal care provided by non-governmental and volunteer organisations
- Private companies

- Other

#### DEGREE OF DEDICATION

@Number of hours a day, on average, receiving care from other persons

#### SATISFACTION WITH CARE RECEIVED

@This studies whether the aid received satisfies her/his needs, and in the case of not receiving personal aid, it studies whether the person needs personal aid or care due to her/his disability or disabilities.

#### MAIN CARER

@In the case that the person receives personal care, this sutides the person who is mainly dedicated to this care, that is, the main carer.

- Sex
- Age
- Marital status
- Highest level of studies completed
- Nationality
- Economic and professional situation
- Sector of her/his previous employment and perspectives for future employment (only for persons employed in the household)
- Number of days a week and number of hours a day in which s/he provides this personal care
- Amount of time providing this care
- Tasks to which s/he is mainly dedicated when assisting or providing care for this person. The following tasks are included:
  - Eating
  - Getting dressed / Getting undressed
  - Personal hygiene / Getting ready
  - Walking or getting around the house
  - Going up or down the stairs
  - Changing incontinence pants due to urinary incontinence
  - Changing incontinence pants due to faecal incontinence
  - Getting in and out of bed
  - Bathing/Showering















































































































































































