INSTITUTO NACIONAL DE ESTADISTICA

Survey on Disability, Autonomy and Dependency Situations 2020
(EDAD 2020)

Methodology

April 2022

Contents

1 Introduction

There is a clear consensus in society, both at home and abroad, of the importance of research into the number, characteristics and situation of people with disability.

13 December 2006 marked the approval of the International Convention on the Rights of Persons with Disabilities. This Convention was the fruit of a lengthy process which saw the participation of UN member states, UN observers, UN bodies and organisations and the Special Rapporteur on Disability, plus national human rights institutions and non-governmental organisations, including organisation of persons with disabilities and their families, who played an important role. The convention also had an important Spanish contingent.

The purpose of the convention was to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms of persons with disabilities, and to promote their inherent dignity. Spain signed and ratified this Convention, which entered into force in our country on 3 May 2008, therefore, since that date this international body of regulations is fully part of the Spanish legal system.

Article 31, “Collection of Data and Statistics,” establishes the obligation of States Parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies in order to give effect to the Convention. The same article states that the information obtained will be used as an aid to evaluate the compliance by Signatory States of their obligation under the Convention, as well as to identify and eliminate the barriers faced by persons with disabilities in the exercise of their rights.

This treatment is reiterated by the Agenda 2030, in which there exists a clear relation between the sense of the SDGs and the purpose of the Convention. Disability is specifically referenced, in addition to the introduction, in various SDGs such as 4, on education; 8, on employment, 10, on reducing inequalities and 11 on the inclusiveness of cities and accessibility of transport. Agenda 2030 stresses the need for data itemised by disability as part of the monitoring of the SDGs.

In this sense, the Survey on Disability, Personal Autonomy and Dependency Situations (EDAD) 2008 produced by the INE, as well as previous macro-surveys (the Survey on Disabilities, Deficiencies and Handicaps - EDDM 1986 and the Survey on Disabilities, Deficiencies and State of Health - EDDS 1999) provided data, which supplied objective knowledge on the reality experienced by persons with disabilities in our country and met the demand for information on the phenomena of disability, dependency and ageing of the resident population in our country by the public administrations and many users, such as Third Sector organisations involved in social action.

The time transpiring from the publication of the last survey on disability and changes that have occurred in the population have led to the presentation of the Green Paper on the updating of the information of the EDAD 2008, as well as the demand for information coming from different Public Administrations and organisations in the Disability Sector.

In this same way, European institutions, through Eurostat, urges Member States to compile data and update information regarding persons with disability, obtaining not only information on their state of health and type of disability in the most detail possible, but also information regarding their socio-economic status, barriers in their social, educational and work environments, as well as possible cases of discrimination.

The 2020 Survey on Disability, Personal Autonomy and Dependency Situations has been designed to meet the previously stated demands.

2 Concept of Disability for the purpose of the EDAD survey

As in EDAD2008, the concept of disability in EDAD 2020 is based on the International Classification of Functioning, Disability and Health (CIF), although with certain different nuances.

Although the ICF uses the umbrella term *disability* to group impairments, activity limitations and restrictions to participation, in the EDAD, the concept of disability has been identified with **major** limitations to performing the activities of daily life that have lasted or are expected to last over a year and that are resulting from a certain impairment.

In the ICF, it is hard to distinguish between “activities” and “participation”, which is why the classification provides a sole list of activities/participation, leaving it up to the user, according to their own operational criteria, to decide upon the difference between the two concepts. In this line, the decision taken for the EDAD was to consider those activities listed in the first seven chapters of the nine which the ICF groups under the “Activities and Participation” component.

The two chapters which have been excluded are “Major Life Areas” (related to activities necessary to participate in education, work, employment and economic activities) and “Community, Social and Civic Life” (related to participating in free time and leisure activities, religious activities, political and public life, etc.).

However, the EDAD has researched the participation in these activities through a set of questions aimed at persons with disability on their involvement in economic activity, education, social networks and contacts.

Once major limitations in the activity have been detected, it has been verified—by means of the degree of severity of each limitation indicated—whether these limitations comply with the disability criteria (major limitation on the activity) for the purposes of the EDAD, or do not comply due to being moderate or slight limitations. In this case, they are not considered a disability.

Regarding impairments, which the ICF considers under the umbrella term of disability, they too have been subject to study, but with a restriction: only those impairments that have led to a limitation in the person’s activity have been researched.

The following chart shows the relation between disability groups contemplated in the EDAD and the corresponding chapters of the ICF:

AGE	Chapter CIF (Activities and Participation)
1. Sight	Body function (visual functions)
2. Hearing	Body function (auditory functions)
3. Communication	3. Communication
4. Learning, applying knowledge and undertaking tasks	Part of chapter 1 (Learning and Applying Knowledge) and part of chapter 2 (General tasks and demands)
5. Mobility	5. Mobility
6. Self-Care	6. Self-Care
7. Domestic Life	7. Domestic Life
8. Interactions and Interpersonal Relationships	8. Interactions and Personal Relationships

3 Working group

The objectives and content of the Disability, Personal Autonomy and Dependency Situations Survey had to meet the demand for information about persons with disabilities and their needs.

For this reason, a multidisciplinary Working Group was created made up of technicians from the INE and experts in the field of disability from the Ministry of Social Rights and Agenda 2030, specifically from the Institute for the Elderly and Social Services (IMSERSO), the Royal Trustees of Disability, and experts from the Spanish Committee of Representatives of People with Disabilities (CERMI), the ONCE Foundation and the NGO Plena Inclusion.

The work of this group focused on the revision of the EDAD 2008 questionnaires to adapt them to the new edition of EDAD 2020, taking into account the information needs, as well as the multi-channel collection method that would be used on this occasion (CAWI, CATI and CAPI); a novelty compared to EDAD 2008, where the information collection channel was exclusively the face-to-face interview with a paper questionnaire (PAPI).

The working group always considered the need to find a balance between the information requested and the reduced burden on the informant.

Once this adaptation of questionnaires was completed, the experts in disability in the Working Group provided assistance to the INE technical team with any conceptual doubts that may have arisen during the project’s implementation. They also provided contacts of people with disabilities to conduct qualitative studies.

Starting from the decision that the concept of disability would remain the same as in EDAD 2008 as well as having the same number of questionnaires (Household, Disability, Limitations and Main Caregiver), the first objective was to review the household questionnaire, one whose purpose was to locate the homes where people with disabilities and/or children with limitations live, as well as obtain socio-demographic information on these households and their members; very valuable information that would provide a comparison of the characteristics of households where people with disabilities live with those which do not contain a person with a disability. The method of collecting this questionnaire would be either online (CAWI) or by telephone (CATI), which meant it was essential to reduce the number of questions, without endangering the objectives, in order for the interview time to be viable with the new collection channels. Once the two versions of the household questionnaire had been agreed upon, the INE conducted qualitative studies and a pilot survey to verify which of the two questionnaires designed best met the objectives sought.

The results and analysis of the pilot test were presented by the INE technicians in the Working Group. These results paved the way for preparing the final version of the Household Questionnaire.

The Expert Group also adapted the individual EDAD 2008 questionnaires to the information needs of 2020. This update was made both in the disability questionnaires (persons aged 6 and over) and limitations (children aged 2 to 5), and also in the questionnaire for the main caregiver.

In the case of individual questionnaires, the collection method would initially not undergo methodological changes; the interview would continue to be in person as in EDAD 2008, except that the paper questionnaire (PAPI) would be changed to an electronic questionnaire (CAPI). Hence, initially no pilot test was needed.

The outbreak of the pandemic during the fieldwork period meant that, in addition to the face-to-face interview (CAPI), as planned, the telephone interview (CATI) had to be considered. This decision did entail a change and for this reason prior studies were carried out by the INE.

Regarding the limitations questionnaire, following international recommendations, the Working Group decided to investigate in EDAD 2020 only children aged 2-5 years, instead of those aged 0-5 years, as was done in EDAD2008, because in children aged 0-1 years it is difficult to differentiate between limitation and developmental delay.

All members of the Working Group agreed on the importance of reducing proxy interviews and obtaining the direct informant, mainly in the individual questionnaire. For this reason, it was decided to make an **easy-to-read version of the disability questionnaire**[1] that would be offered to people with intellectual disabilities so that they could answer it themselves without the intervention of a proxy. The ONCE Foundation and the NGO Plena Inclusion conducted the work of translating the questionnaire into easy-to-read formats.

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[1] Easy-reading is the adaptation that allows for a simpler way of reading and understanding content. The method transforms complex sentences into short sentences and opts for easily understood vocabularies without changing the meaning of the initial text.

4 New methodological focus in the EDAD 2020 survey

In recent years, INE has worked on the development and implementation of different methods of information collection in household surveys, moving from exclusively personal interview collection (CAPI) to web questionnaires (CAWI) and telephone interviews (CATI), with the frequent use of multi-channel collection.

The data collection method for EDAD 2008 was a personal interview with a paper questionnaire (PAPI). Initially, a household questionnaire was completed to obtain socio-demographic information on all household members and to detect if any person aged 6 years and over had a disability and/or if any child aged 0-5 years had any limitation. An individual questionnaire was then completed for each person with a disability and for each child with a limitation. The number of questions to detect whether or not a person aged 6 and over had a disability was 44 and for children aged 0-5 with limitations it was 18.

In EDAD 2020, multi-channel collection is incorporated, considering it convenient to carry out the household questionnaire using the CAWI, CATI and paper questionnaire sent by post. Once the persons with a disability or limitation have been located, the information from the individual questionnaire would be collected through a CAPI interview. While this was the initial decision, the outbreak of the pandemic during fieldwork necessitated a CAPI and CATI collection in this second phase.

The new collection channels required a reduction in the size of the household questionnaire because the length of the CAWI and CATI interview had to be shorter than the EDAD 2008 face-to-face interview, in order to maintain the informant's attention and ensure the quality of the information. This reduction of the questionnaire affected both the socio-demographic variables and the questions aimed at capturing persons with a disability or limitation and their type of disability.

The working group determined the questions to be included in the household questionnaire concerning household characteristics and socio-demographic information on each member of the household, basing this decision on the essential information to be included for certain analyses and excluding information that could be obtained from other sources.

In relation to the questions on disability or limitations, one of the priority and most complex objectives in the design of the new questionnaire was to ensure that reducing the number of questions in the household questionnaire or modifying the wording of the questions would capture persons with disabilities or limitations and their disabilities or limitations with the same quality as the EDAD 2008 household questionnaire.

A detailed analysis of the relevance of each of the 44 questions in the EDAD 2008 household questionnaire to capture persons with disabilities aged 6 and over and each of their disabilities was carried out. This study and the advice of the working group's disability experts was the fundamental basis for designing two proposed questionnaires, one with 10 questions and the other with 25 questions to replace the 44 questions of EDAD 2008.

There was also discussion about the possibility of incorporating graded responses ranging from "No difficulty" to "Very difficult or unable to do it" rather than dichotomous responses. Thus, in line with the definition, a person with a disability would be a person who has great difficulty in performing an activity or is unable to do it.

Finally, for each of the two questionnaire proposals, a version with dichotomous answers and a version with graded answers were considered.

In the same way, the questions aimed at children aged 2 to 5 years with limitations were reduced to 10 questions.

Qualitative pre-tests were carried out with these proposed new questionnaires for both the disability and limitations questions. A pilot survey was also conducted to test questions on disability among people aged 6 and over.

4.1 QUALITATIVE STUDIES (DISABILITY)

The qualitative studies were carried out using the four questionnaire models mentioned above: M1R1, M1R2, M2R1 y M2R2. The difference between M1 and M2 was the number of filter questions, i.e. the number of questions aimed at detecting persons aged 6 and over with disabilities. Model M1 contained 10 questions and model M2 contained 25 questions. The R1 models corresponded to the dichotomous response questionnaires (Yes/No) and the R2 models had a graded response with 4 options (Total difficulty, Much difficulty, Some difficulty and I cannot do it). The questions in all models included at least one question related to each of the types of disability under study: vision, hearing, communication, learning, mobility, home life, self-care and personal relationships.

The questions on household composition and socio-demographic data for each household member were the same in all model questionnaires.

The qualitative study was to shed light on whether the comprehensiveness and quality of the filter questions of the above models via CAWI and/or CATI met the same objectives as the PAPI household questionnaire used in EDAD 2008, i.e. it allowed to capture households where persons with disabilities resided, it allowed to identify these persons as well as their types of disabilities.

The study should also make it possible to analyse qualitatively, for each type of disability, whether the information was more correctly collected with the M1 model or with the M2 model.

In the case of CAWI, problems encountered in filling in the electronic questionnaire during navigation could also be assessed.

Contributing informants with and without disabilities, with different levels of education and a wide range of age groups were identified. People with disabilities had different types of disabilities, a feature that would allow for a more accurate analysis of the whole questionnaire. The number of collaborators was 22, who were randomly assigned to each of the models to be tested.

At all times the participants were informed about the confidentiality of the procedure guaranteed by statistical confidentiality. All agreed to participate.

In the case of the CAWI interview, the respondent completed the questionnaire at INE Headquarters, in a room with a computer with access to the IRIA portal, where he/she accessed the web questionnaire. They were given a letter like the one they would receive at home in case of the real survey, with the url and the access codes to the web questionnaire. The INE team specialised in the cognitive pre-tests followed the completion of the questionnaire via video conference, in order to see the difficulties and doubts that the respondent had when filling in the answers. At the end of the questionnaire, a personal interview was conducted to assess the understanding of the questionnaire, difficulties in answering the questionnaire and the usability of the application.

In the case of CATI interview, the informant was contacted and the telephone interview was conducted. Subsequently, the respondent travelled to INE Headquarters to conduct the personal interview for the same purpose as in the case of the CAWI interview.

The qualitative studies made it possible to refine the wording of some questions to make them easier to understand, to include examples in the questions themselves, as suggested in some cases by the collaborating informants, and also made it possible to reach the conclusion to discard the dichotomous response, as the informants unanimously considered the gradual response to be more appropriate in order to make their answer more precise.

Aspects that could be improved in terms of the usability of the application were also detected, such as the location of buttons (continue button, back button, help button...), as well as the wording of the introductory texts to the different blocks.

Suggestions were received for improvements in the wording of the letter sent by the INE to the selected persons.

All the improvements and findings from the qualitative studies were introduced into the M1R2 and M2R2 models, which were, after discarding the dichotomous response, the two types of questionnaire to be tested in the pilot test.

In relation to the accessibility of the web questionnaire, the INE was advised by the ONCE, which carried out a study assessing possible navigation problems.

4.2 PILOT TEST (DISABILITY)

The aim of the pilot test was to analyse whether the methodological change with respect to EDAD 2008 affected the collection of information on the number of persons with disabilities and their disabilities.

The new methodology encompasses both the change of collection channel of the household questionnaire, CAWI or CATI versus PAPI, and the new questionnaires adapted to the new collection methods and already tested in the qualitative pre-tests.

The pilot test was to determine which of the two questionnaires M1R2 or M2R2 best captured people with disabilities and their disabilities. The questions of the two model questionnaires were distributed across the eight disability blocks, so that the pilot test would also allow to analyse whether a type of disability was better captured with the M1 model or with the M2 model. Depending on the results, the household questionnaire in the actual survey could be M1R2, M2R2 or a combination of both.

The pilot test sample was 6,000 dwellings, divided into two independent samples of 3,000 units each and geographically distributed between the provinces of Jaén, Madrid and Valladolid as follows:

- 1,560 households in the province of Jaén

- 3,000 households in the province of Madrid
- 1,440 households in the province of Valladolid

These three provinces were selected because they are provinces where the prevalence of disability in 2008 was similar to the national prevalence.

A letter of introduction was sent to the selected households explaining the study to be carried out and inviting them to collaborate.

In order to achieve the objectives pursued, the pilot test was conducted in two phases. First, the CAWI or CATI interview was carried out with the new questionnaires, assigning each independent sample a different model.

The National Commission of Markets and Competition (CNMC) provided telephone numbers, necessary for the CATI interview, of the persons who were registered in the dwellings that formed part of the sample, obtaining with this procedure at least one telephone number for 83% of the households in the sample.

The fieldwork was coordinated by INE technicians from different Provincial Delegations and the telephone interviews were conducted by staff from the INE CATI unit. Both technicians and interviewers received training courses by people from the Subdirectorate General for Sectoral Social Statistics and the Subdirectorate General for Data Collection of the INE.

In order to be able to compare with DIDSS 2008, in a second phase of the pilot study, households that had participated with the CAWI or CATI interview were contacted again and interviewed again, this time using the CAPI channel and the EDAD 2008 household questionnaire[2]. The aim was to replicate the 2008 context in order to analyse the potential impact of change.

In this way, it was possible to compare whether the same person with disabilities and their disabilities were captured both by the new questionnaires via CATI or CAWI and by the EDAD2008 questionnaire via CAPI.

This comparison and analysis allowed for the development of the EDAD2020 household questionnaire, in particular the questions aimed at capturing persons aged 6 and over with disabilities and their disabilities. As expected, the final questionnaire included in some of the disability blocks the questions from questionnaire M1 and in others the questions from M2, all based on the results of the pilot survey.

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[2] The EDAD 2008 household questionnaire with the 44 questions to detect a person with a disability was previously updated and revised according to current needs.

Domains	**M1 model questions**	**M2 model questions**	**EDAD 2020 household questionnaire questions**
Sight	1	3	3
Hearing	1	2	2
Communication	1	3	3
Learning	1	3	1
Mobility	2	4	4
Self-Care	2	5	2
Domestic Life	1	2	2
Interactions and Personal Relationships	1	3	1
TOTAL	**10 questions**	**25 questions**	**18 questions**

Persons with disabilities for the purposes of this survey, and following international recommendations, are those who declare having great difficulty or total difficulty in any of the 18 questions in the household questionnaire, aimed at capturing persons aged 6 years old and over with disabilities, and who subsequently confirm this in the individual questionnaire, in which they are asked in greater detail about said disability.

4.3 QUALITATIVE STUDY (LIMITATIONS)

Once the questions in the household questionnaire aimed at capturing households where children with limitations resided, as well as their limitations, a qualitative study similar to the one conducted with the disability questions was carried out. On this occasion, the aim was to ensure that the completion of the questionnaire through the new channels (internet and telephone) met the objectives for which the questionnaire had been designed. On this occasion only one model questionnaire was available.

The qualitative study was to shed light on informants' understanding of the questions and on whether the questions in the questionnaire via CAWI or via CATI correctly captured households where children with limitations live as well as their limitations.

The study was carried out by INE's team specialised in qualitative studies. 13 families collaborated and 15 children aged 0-5 years were investigated. Collaboration was voluntary and families were contacted who had children in this age range both with and without limitations.

Although it was concluded that the questionnaire met the objectives, the study and the informants' input led to improvements in the wording of some questions to make them more comprehensible.

The answers in this case would be dichotomous. A child with limitations for the purposes of this survey, and following international recommendations, is a child who answers affirmatively to any of the questions in the household questionnaire designed to capture children with limitations and who subsequently confirms this in the individual questionnaire in which the limitation is probed in more detail.

Although the limitations questionnaire would only be completed for children aged 2 to 5 years who had been detected in the household questionnaire as children with difficulties or limitations in some activity typical of their age, the household questionnaire includes some questions also addressed to children of an early age (0-1 year), hence its inclusion in the qualitative pretests.

5 Objectives of the EDAD2020 survey

The general objective of EDAD2020 is to meet the demand for information from public administrations and numerous users, such as third-sector social action organizations, by providing a statistical basis for planning policies for people with disabilities that promote personal autonomy and prevent dependency situations. In addition, it is designed to obtain information on the health of carers of people with disabilities, as well as the time spent on care-giving and the impact on their personal life, both work and leisure.

The EDAD2020 edition aims to update the information from EDAD 2008 and therefore also considers the philosophy of the International Classification of Functioning, Disability and Health (CIF).

The **specific objectives** that this survey hopes to achieve are to:

1. Estimate the number of people with disabilities residing in family dwellings in Spain, both at national level and by Autonomous Community.
2. Know the number and type of disabilities of people with disabilities.
3. Estimate the number of households in which a person with a disability resides.
4. Know the different types of limitations in the activity of people with disabilities, as well as the severity of these limitations.
5. Investigate the use or need for technical or personal aids to overcome the limitation and the severity of these limitations using such aids.
6. Identify the impairments leading to the disability.
7. Find out the general state of health and certain diagnoses of persons with disability.
8. Evaluate equal opportunities (discrimination) for people with disabilities in the workplace, education, mobility accessibility, and technological accessibility.
9. Know the social and economic benefits received by people with disabilities.
10. Find out the expenditure on disability in households where people with disabilities live.
11. Investigate possible socio-economic differences between households with persons with disabilities and households without persons with disabilities.
12. Know the situation of the main carers of people with disabilities.

6 Phases of the Survey

The study has been performed in two phases:

The first phase aims to locate homes where people with disabilities and/or children with disabilities live, and to identify these people and their disabilities. In order to identify people with disabilities or children with disabilities, the first-phase questionnaire, called the Household Questionnaire, contains a block of filter questions about possible disabilities and limitations for each household member. These questions have graded answers on the difficulty in performing the activity under investigation for adults and dichotomous answers for children. If the person shows great difficulty or is unable to perform a task or activity, he/she is considered a person with a disability for the purposes of this survey and would therefore be investigated in the second phase. In the case of children, those with an affirmative answer to the limitation-related questions are investigated in the second phase.

The second phase aims to obtain more detailed information, through individual questionnaires, on people aged 6 and over with disabilities detected in phase 1. This information will not only refer to their state of health, which will be investigated for the deficiency underlying the disability, but also to the availability or need for technical or personal aids, accessibility, social benefits, education, employment, personal relationships, social environment, care, etc. In the case of children with limitations aged 2 to 5 detected in phase 1, information will be obtained on the deficiency underlying the limitation, on the availability and need for personal and technical aids, and on the care they receive.

In this second phase, information will also be collected on the primary caregivers of persons with disabilities and/or children with limitations.

Three questionnaires were designed for this second phase: Disability Questionnaire (persons aged 6 years and over), Limitations Questionnaire (children aged 2-5 years) and Carer Questionnaire (for the main carer).

7 Research areas

Population scope

The research is aimed at all persons residing in main family households. We distinguish two age groups: children from 2 to 5 years old, a group in which those with some limitation are investigated, and people aged 6 and over, a group in which those with some disability are investigated. Children aged 0-1 are excluded from this study according to international standards, as it is not possible to discern in this age group between developmental limitation and developmental delay.

Geographical scope

The geographical scope is the entire national territory.

Temporal scope

The collection period for Phase 1 ran from August 2020 to January 2021 and for Phase 2 from April 2021 to October 2021.

8 Sample Design

8.1 SAMPLE TYPE

A stratified two-stage sampling process has been used. The first stage units are the census sections. The second stage units are the main family households. Within them, no sub-sampling has been carried out, and all households and persons who have their usual residence in them have been investigated.

The sample selection framework was based on the area framework formed by the list of existing census sections as of 1 January 2020. For the second stage units, the list of main family households in each of the sections selected for the sample is used, obtained from the most up-to-date Continuous Population Register available.

The sections are grouped into stratum within each Autonomous Community according to the size of the municipality to which they belong.

The following stratum have been taken into account:

Stratum 0: Municipalities with 500,000 inhabitants or more.

Stratum 1: Provincial capital municipalities with less than 500,000 inhabitants.

Stratum 2: Municipalities with between 100,000 and less than 500,000 inhabitants (except the above)

Stratum 3: Municipalities with between 50,000 and less than 100,000 inhabitants (except the above)

Stratum 4: Municipalities with between 20,000 and less than 50,000 inhabitants (except the above)

Stratum 5: Municipalities with between 10,000 and less than 20,000 inhabitants.

Stratum 6: Municipalities with less than 10,000 inhabitants.

An independent sample has been designed for each autonomous community to represent it, as one of the survey's objectives is to provide data at this level of disaggregation.

8.2 SAMPLE SIZE. ALLOCATION

In order to meet the survey's objectives of being able to provide estimates with a certain degree of reliability on a national and Autonomous Community level, and taking into account the precision of the results obtained in the previous disability survey carried out in 2008, an initial sample size of **110,130** households has been determined, distributed in **3,671** census sections, with **30** being the number of incumbent households selected in each section.

The distribution of the sample among the Autonomous Communities has taken into account the size of the Community in terms of population, and a minimum average level of precision in all Communities. For these purposes, a compromise between uniform and proportional affixation has been used.

The distribution of the number of sections selected by Autonomous Community is as follows:

Autonomous Community	Number of census sections
Andalucía	420
Aragón	170
Asturias, Principado de	140
Balears, Illes	145
Canarias	195
Cantabria	115
Castilla y León	300
Castilla - La Mancha	195
Cataluña	335
Comunitat Valenciana	320
Extremadura	145
Galicia	250
Madrid, Comunidad de	330
Murcia, Región de	151
Navarra, Comunidad Foral de	116
País Vasco	180
Rioja, La	114
Ceuta and Melilla	50
TOTAL	**3,671**

The allocation between stratum is strictly proportional to the size of the stratum.

8.3 SAMPLE SELECTION

For the initial theoretical sample, sections are selected within each stratum with probability proportional to their size. The households, in each section, with equal probability through systematic sampling with random start.

From among the units not contacted in the CATI/CAWI collection phase, a stratified sub-sample was made according to census information of 85% of the units susceptible of being selected.

8.4 ESTIMATORS

To estimate the main characteristics investigated in the survey, ratio estimators have been used to which calibration techniques are applied.

The final estimator has been formed taking into account the following points:

The probability of selection based on the sample design

The design probability that a household in stratum h is in the sample is:

$$P(V_{ih}) = \frac{v_h^t}{V_h}$$

Where:

V_h: Number of households in stratum h.

v_h^t: Number of households in the theoretical sample and in stratum h.

Using the total population in each stratum as information, the factors of the ratio estimator would be:

$$f_h = \frac{P_h}{p_h^t}$$

Where:

P_h: Number of persons in the stratum h.

p_h^t: Number of persons in the theoretical sample and in stratum h.

Correcting the lack of response

In order to minimise the error made when estimating total and percentage of disability in sub-populations, a non-response correction is made for variables that are highly correlated with disability. In this way, sub-strata are formed to correct the non-response. Four sub-strata are formed within each stratum:

- **Sub-stratum 1.** Households with a maximum age of less than 42 years.
- **Sub-stratum 2.** Households with a maximum age between 43 and 56 years.
- **Sub-stratum 3.** Households with a maximum age between 57 and 72 years.
- **Sub-stratum 4.** Households with a maximum age of over 73 years.

Previous age limits have been obtained by using logistic regression and decision tree models.

Finally, with the non-response correction, we obtain the following factors:

$$f_{hg} = \frac{P_h}{p_h^t} \cdot \frac{p_{hg}^t}{p_{hg}}$$

Where:

p_{hg}: Number of persons in the effective sample, in stratum h and sub-stratum g.

p_{hg}^t: Number of persons in the theoretical sample, in stratum h and sub-stratum g.

Also, within the subset of people who in Phase I have some kind of disability, there is a percentage who did not participate in the survey in Phase II.

To correct for this non-response between phases, a re-weighting factor f_{hg}^* is calculated for people with disabilities in both phases taking into account the estimated proportion of those who were disabled in phase II. For people without disabilities $f_{hg}^* = f_{hg}$.

Calibration

The factor is adjusted to balance the sample to the population by age and sex groups, i.e. a new weight is calculated f'_{hg} which is close to f^{*}_{hg} and which checks:

$$\sum_h \sum_g f'_{hg} Y_{hg} = Y$$

for the following marginal variables Y at the level of each autonomous community: 28 sex and age groups, total foreigners and 5 household size groups.

Thus, the final estimator of a characteristic X will be:

$$\hat{X} = \sum_h \sum_g f'_{hg} X_{hg}$$

Where X_{hg} is the total number of persons in stratum h and sub-stratum g who have characteristic X.

8.5 SAMPLING ERRORS

The Jackknife method is used to obtain sampling errors.

This method is based on the creation of sub-samples where each of these is obtained by eliminating a primary unit from the total sample.

From each subsample, or jackknife sample, we obtain the estimate of the characteristic whose sampling error we want to obtain. This estimate is calculated in the same way as the estimate for the full sample, i.e., including non-response and calibration adjustments.

Once all the estimates have been calculated with each of the jackknife samples, as well as the estimate with the complete sample, the variance estimator is given by the expression:

$$\hat{V}(\hat{Y}) = \sum_h \frac{n_h - 1}{n_h} \sum_{j \in h} \left(\hat{Y}_{(hj)} - \hat{Y}\right)^2$$

where:

$\hat{Y}_{(hj)}$ is the estimate based on the jackknife sample obtained by removing primary unit j from stratum h from the complete sample.

$\hat{Y}$ is the estimate based on the full sample.

n_h is the number of primary units in stratum h.

The relative sampling error in percentage (coefficient of variation) is published in the tables, which is given by the following expression:

$$C\hat{V}(\hat{Y}) = \frac{\sqrt{\hat{V}(\hat{Y})}}{\hat{Y}} \,.\, 100$$

9 Collection of information in the EDAD 2020 survey

9.1 GENERAL APPROACH

The collection of the EDAD 2020 study was organised in two phases. The first phase (phase 1) took place between the months of **August 2020 and January 2021**. In this phase, through the household questionnaire and using the CAWI, CATI and paper questionnaire sent by post, the aim was to locate households in which persons with disabilities or children with limitations lived, as well as their disabilities and limitations. The second phase (phase 2) ran from **April 2021 to October 2021** and aimed to obtain more detailed information from people who had reported a disability or limitation in phase 1 and their main carers. This information was collected through three questionnaires: disability questionnaire (for persons aged 6 years and older), limitations questionnaire (for children aged 2-5 years) and caregiver questionnaire (for the main caregiver). Initially the type of interview in phase 2 would be a personal interview with electronic questionnaire (CAPI), the pandemic situation and the reluctance of informants to allow an interviewer into their home made it necessary to enable the CATI (telephone interview) channel in phase 2.

Although the concept of person with disability in EDAD 2020 does not coincide exactly with the concept of person with disability in the State Database of People with Disabilities (BEPD), in the organisation of the fieldwork it was decided to take advantage of the information in the BEPD to reduce the burden on the informant. After analysing the results of the pilot survey, it was observed that people who in the BEPD had a recognised disability certificate equal to or higher than 75% and/or a degree of dependency type II or III, with a high probability were a person with a disability according to the concept of EDAD 2020. For this reason, the households in the theoretical sample in which at least one person included in the base with the aforementioned conditions lived, would go directly to phase 2, carrying out both the household questionnaire and the individual questionnaires in this phase, in this way the contact with the household would be limited to one instead of two in order to carry out the complete interview.

A sub-sample of households not contacted in Phase 1 would also go to Phase 2, in order to reduce non-response caused mainly by the collection method and the pandemic situation.

9.2 COLLECTION OF THE EDAD 2020 SURVEY PHASE 1

The first phase of the collection was carried out by asking the questions that appear in the household questionnaire to a person of legal age who was sufficiently informed about the situation of the persons residing in the selected household.

Three collection methods were established:

- CAWI: The electronic questionnaire was completed by the respondent himself/herself and is available on the Internet at www.iria.ine.es.
- CATI: consisting of computer-assisted personal interviewing, in which interviewers called households to conduct the telephone interview. Respondents could also call the toll-free number indicated in the letters previously sent to them announcing the survey, to request completion of the survey through this channel.
- POST: data were collected through a paper questionnaire that was sent by post to the households.

On the other hand, in order to organise the fieldwork, both in terms of the flow of calls to the toll-free 900 line, the CATI interviews and the sending and receipt of paper questionnaires, the sample was divided into four blocks comprising different Autonomous Communities.

The collection was designed according to three planned stages in each sample block, with simultaneity in the collection of successive blocks:

- FIRST STAGE: CAWI

  The first stage started in August 2020, enabling the online collection channel for the first block of sample units. In order to access the electronic questionnaire, informants had to enter some codes that were included in the letters previously sent to all the dwellings selected in the sample, with the exception of households in which a BEPD person with the aforementioned degree of disability or dependency lived.

  After a set period of time, the agents began to make calls to all dwellings for which a telephone was available and which had not completed the questionnaire, to encourage them to complete it online, at which point the CATI interview could be carried out. The passwords included in the initial letter, which allowed access to the online portal for completing the form, were used as a reference to ensure the informant was certain that the caller was speaking on behalf of the INE.

  The CAWI channel was successively opened for the rest of the blocks.

- SECOND STAGE: CATI

  Again, after a set time had elapsed since the beginning of the CAWI phase of each block, those units in the block that had not completed the questionnaire were sent a second, reminder letter. If a telephone number was available for the dwelling, they were also informed that an agent would soon contact them to conduct the interview by telephone if they did not complete the questionnaire online. This letter provides a new opportunity to fill in the CAWI, again including the keys to access the web questionnaire.

  Thus, several days after the reminder letter was sent, the dwellings were contacted by telephone to complete the questionnaire by CATI, although the possibility of completing it online was kept open if the dwelling preferred to do so.

The usual working method for a CATI operator is what we call "new call," which indicates the interviewer's willingness to make the call automatically generated by the algorithm. This algorithm searches for the most likely time to conduct the interview, based on the information available. Thus, before generating a call, it takes into account, among other things:

- The existence of appointments in the household to call at a specific time
- The existence of filters with interview time preferences
- Whether or not the household has already been called and, if so, how long it has been uncalled for
- The time of the previous interview attempt

The alternative work method is what we call “personal”. In this case, the operator calls one of the households assigned to him/her by the supervisor for some reason.

- THIRD STAGE: POST

After a certain time had elapsed since the beginning of the CATI phase of each block, the third stage began, in which the paper questionnaires were sent by post to households that had not completed their interview in the previous channels. A postage-paid envelope was included in the mailing so that the completed questionnaire could be returned to the household. Once they were received back, they were recorded by agents in the application, which detected if the information provided had inconsistencies that needed to be corrected or if there was missing information that needed to be completed, in which case the agents would call the informants in order to clean up.

The electronic questionnaire was designed using the IRIA (Integration of Information Collection and Administration) application, including workflows, critical errors, questionnaire validity checks, prompts, and pre-recorded information.

9.3 COLLECTION OF THE EDAD 2020 SURVEY PHASE 2

The second phase collection was carried out by initially asking the questions appearing in the Household questionnaire, in case the Household questionnaire had not been collected in phase 1[3]. Otherwise, the interview was started with a Disability questionnaire or a Limitations questionnaire, as appropriate.

The Disability questionnaire was addressed to each of the persons aged 6 years and over for whom it had been indicated that they had difficulty in any of the questions relating to the different types of disability asked about in the Household questionnaire. This questionnaire had to be answered, whenever possible, by the person to whom it was addressed, although a proxy was admitted in the absence of the person under four circumstances: prolonged absence, disability or serious illness that prevented him/her from answering, lack of knowledge of the language or being a minor.

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[3] In the case of households in which a member of the household had a degree of disability of 75% and/or degree of dependency of type II or III and in the case of households that formed part of the sub-sample of non-contacted in phase I.

The Limitations questionnaire was addressed to each child in the household between 2 and 5 years of age who was reported to have difficulties in any of the questions related to the different types of limitations investigated in the Household questionnaire. This questionnaire had to be answered by a person of legal age who was sufficiently informed about the minor's situation.

Derived from the individual questionnaires above and if they stated that the person was receiving care, an additional questionnaire had to be completed: the Main Caregiver questionnaire. The questionnaire was to be answered by the caregiver himself/herself. Failing this, proxy was allowed under three circumstances: prolonged absence, night carer only, or lack of language skills.

Phase 2 was designed to be conducted by face-to-face CAPI interview, however, the pandemic situation made it difficult for an interviewer to visit the person directly, so the feasibility of CATI interviewing was explored in Phase 2. For this purpose, different tests were carried out, assessing whether the length of the telephone interview guaranteed the quality of the information, whether it kept the informant's attention until the end and whether it was necessary to adapt any questions to the new channel. The study showed that the CATI interview was feasible and for this reason two collection methods were established:

- CATI: consisting of computer-assisted personal interviewing, in which interviewers called households to conduct the telephone interview. Respondents could also call the toll-free number indicated in the letters previously sent to them announcing the survey, to request completion of the survey through this channel.
- CAPI: computer-assisted personal interview, in this case carried out through a personal visit by an agent with a handheld device.

On the other hand, in order to facilitate the organisation of the collection, both in terms of the flow of calls to the toll-free 900 line, the carrying out of CATI interviews, and the organisation of the fieldwork, three geographical areas were established, comprising different Autonomous Communities.

The collection was designed according to two planned stages in each area. With the following scheme, there was a partial overlapping of the tasks to be carried out in the different areas:

- FIRST STAGE: CATI

  The first stage began in April 2021, starting in zone 1 with a telephone contact with the households for which a telephone was available, to whom a letter had previously been sent announcing the survey and who would soon receive a call from an agent to conduct the interview by telephone. This stage was similar to that described in phase 1 of the survey.

  The CATI phase was then launched for the rest of the zones.

- SECOND STAGE: CAPI

  After a period of time had elapsed since the start of the CATI stage in each zone, the second stage, or CAPI stage, began. Prior to the start of the survey, a letter was sent to households that had not completed their questionnaire, announcing the survey in case they had not received a previous letter, and informing them that they would soon receive a visit from an agent, duly accredited, to complete the questionnaire by means of a personal interview. The letter contained an identification number of the household, which the household could request from the person visiting them in order to be sure that it was an interviewer on behalf of the INE.

During the CAPI stage, interviewers visited the selected households to conduct the interviews and fill in the questionnaires, according to the work quota that had been previously assigned to them.

As in phase 1, the electronic questionnaire was designed through the IRIA (Integration of Information Collection and Administration) application including flows, serious errors, valid questionnaire checks, prompts and pre-recorded information.

9.4 ORIGIN OF CATI INTERVIEW PHONES

Telephone numbers for CATI interviews are obtained from two different sources. On the one hand, based on the information provided by the CNMC on the telephone numbers owned by the adults registered in the dwellings that form part of the first interview sample selected in the survey, both the phase 1 sample, for making the calls in the first phase, and the phase 2 sample, for making the calls in the second phase.

For this purpose, a list of persons identified by DNI (or NIE) is sent to the CNMC, which corresponds to the persons registered in each of the dwellings in the sample. To each individual, the CNMC assigns the telephone numbers (landline or mobile) of which he or she is the holder.

Therefore, the fact that a person is assigned a telephone number in this file does not necessarily mean that he/she is the person who uses the line, but rather that he/she is the holder of the telephone number as stated in the telephone contract.

On the other hand, the telephone numbers provided by the AEAT were also used to carry out phase 2, mainly for those dwellings in the phase 2 sample for which none were available. For this purpose, a list of persons identified by DNI (or NIE) is sent to the AEAT, which corresponds to the persons registered in each of the dwellings in the sample. For each individual, the AEAT assigns the telephone numbers (landline or mobile) available to them, based on past personal income tax returns.

9.5 TRAINING COURSE FOR INTERVIEWERS

Before starting the collection work in both phase 1 and phase 2, INE officials gave training courses to those responsible for the company in charge of the collection. They were also responsible for the training of the personnel under their charge in the respective zones.

The pandemic situation forced the courses to be held online.

These courses explained the methodological concepts and theoretical considerations of the survey content, the handling of the different functionalities of the collection, monitoring and control application, the organisation of the different channels and the handling of the handheld devices. The procedure for administering the questionnaire, the rules for conducting the interview, the rules for carrying out the fieldwork (collection and inspection), the incidents in the collection, their treatment and any other practical considerations that were considered necessary were also explained, supporting the presentation with explanatory cases on the completion of the questionnaires and the work report.

The training courses were supported by the corresponding manuals developed by the Promoter Unit and the Data Collection Unit, incorporating all aspects of data collection.

All the material developed for the course given by INE was given to the company for use in training their staff.

It was also explained to the interviewers the importance of their mission and the relevance in data collection of the correct conduct of the interview and the handling of those factors that influence people's collaboration and the quality of the answers they provide.

The importance of getting the direct informant, avoiding the proxy interview, was stressed, and the availability of the individual questionnaire in easy-to-read format for those people with intellectual disabilities who needed it was reminded.

The training courses included the collaboration of experts in the field of disability and members of the working group of EDAD who focused on giving guidelines on how to conduct an interview with people with disabilities depending, in some cases, on the type of disability.

9.6 VOLUNTARY NATURE OF THE SURVEY

This statistical operation investigates variables included in Article 11.2 of the LFEP (ethnic origin, political opinions, religious or ideological convictions and any that affect personal or family privacy) and is therefore voluntary.

10 Structure of the questionnaires and characteristics under study[4]

Below is a description of the structure and characteristics of the study subject in each of the 4 questionnaires:

- HOME QUESTIONNAIRE
- DISABILITY QUESTIONNAIRE
- LIMITATIONS QUESTIONNAIRE
- MAIN CARER QUESTIONNAIRE

HOME QUESTIONNAIRE

The aim of this questionnaire is to locate persons aged 6 years and over with disabilities and children aged 2-5 years with limitations, about whom more information will be obtained later through the individual questionnaires. To this end, a series of questions on limitations or difficulties is included for all disability groups.

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[4] The questionnaires are available on the INE website

In addition, in order to be able to carry out an analysis of the socio-economic differences of households with persons with disabilities and households without persons with disabilities, the survey investigates, through this questionnaire, the following variables for all household members:

- Sex, age, nationality and marital status
- Highest level of education attained
- Accessibility, Equipment and Housing Conditions
- Net household income[5]

In addition, information is obtained for all members of the household on whether they have a recognised degree of disability and/or a situation of dependency, as well as whether they receive a pension for permanent incapacity.

DISABILITY QUESTIONNAIRE

The study of disability characteristics has focused on the population aged 6 and over, since the prognosis for development in children is uncertain, and only age-appropriate limitations in the 2 to 5 year old group are analysed.

The following disability areas are researched:

1. Sight
    - Complete lack of vision
    - General visual tasks
    - Detailed visual tasks
    - Other vision problems
2. Hearing
    - Total hearing loss
    - Hears loud noises
    - Hears what is said in a conversation
3. Communication
    - Utters spoken phrases
    - Receives spoken phrases
    - Communicates via written messages
    - Communicates via gestures, signs or symbols
    - Limitations to communication due to specific problems of a cognitive or intellectual nature
    - Communicates via telephone

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[5] The variable "Net household income" is obtained from administrative records

- Communicates via remote written communication systems (email, WhatsApp or social media)

4. Learning, knowledge application and task development
   - Pays attention by looking or listening
   - Learns simple things
   - Performs simple tasks due to a mental problem or intellectual disability
   - Performs complex tasks due to a mental problem or intellectual disability
5. Mobility
   - Changes basic body postures
   - Maintains position of the body
   - Moves around inside the home
   - Moves around outside the home
   - Moves around using transport as a passenger
   - Drives vehicles
   - Handles, picks up and moves objects
   - Has fine motor skills
6. Self-Care
   - Washes by oneself
   - Basic body care
   - Personal intimate hygiene
   - Gets dressed and undressed
   - Eats and drinks
   - Cares for one's own health: follows medical prescriptions
   - Avoids hazardous situations
7. Domestic life (only for persons over the age of 12)
   - Administers the household budget
   - Shopping
   - Prepares meals
   - Carrying out other household chores
8. Interactions and Interpersonal Relationships
   - Shows affection or respect towards others
   - Relates with unfamiliar people
   - Relates with family, friends and other familiar people
   - Relationships (only for those over 16 years of age)

For each disability, the impairment of origin is investigated.

In addition, the following study variables are considered, distributed in eight blocks:

1. Health, diagnostics and health benefits
    - Overall health status
    - Diagnosis of diseases
    - Consultations or health services needed (received and not received)
    - Perception of discrimination in health consultations or services
2. Social and economic benefits
    - Social services needed (received and not received)
    - Economic benefits or compensation due to the disability
    - Tax benefits received due to disability
3. Education, schooling and studies in progress
    - Schooling (those under 16 years of age)
    - Studies in progress (people with disabilities aged 16 and over who are studying)
    - Adaptations (physical and curricular) of the school due to the disability
    - Absence from school due to disability
    - Perception of discrimination in the centre due to disability
    - Perception of harassment or cyber-bullying due to disability
4. Employment and work status
    - People currently working:
        - Change of occupation or business due to disability
        - Type of employment, type of contract and current working hours
        - Modification of working hours due to disability
        - Change of occupation or job due to disability
        - Occupation of the person and activity of the company he/she works for
        - Measures to promote employment
        - Workplace accommodations due to disability
        - Perception of discrimination in the workplace due to disability
        - Perception of workplace harassment due to disability in the workplace
    - People who do not work:
        - Reason for leaving employment (if previously employed)
        - Reason for not working (if never worked)
        - Time out of work (if previously worked)
        - Channels used for job search (if seeking employment)

    - Unemployment benefits (if previously employed)

5. Relationships, leisure and social environment
    - Contact with relatives
    - Contact with friends and neighbours
    - Activities during your leisure time
    - Activities you would like to do but can't because of disability
    - Perception of discrimination during leisure time and social relations on the basis of disability
    - Participation in disability related associations/non-governmental organisations
    - Perception of discrimination in exercising civil and political rights
6. Accessibility and travel
    - Accessibility problems (housing, building, housing surroundings) due to disability
    - Carrying out adaptations in the house, building and surroundings to facilitate accessibility
    - Need to change housing due to disability
    - Accessibility problems in public buildings, public roads, squares and gardens
    - Problems of accessibility to transport
    - Perception of discrimination in transport due to disability
    - Limitations of use of information and communication technologies due to disability
    - Assessment of the improvement of aspects of daily life thanks to the availability and use of new information and communication technologies
7. Care, support and personal assistance
    - Assistance and personal care received
    - Number of hours of assistance and/or care received
    - Kinship relationship to caregivers
8. Disability-related expenditure
    - Expenditure type
    - Annual expenditure due to disability

LIMITATIONS QUESTIONNAIRE

In this questionnaire the age-specific limitations for the age group 2-5 are investigated. Early age children (under 2 years) are excluded on the recommendation of national and international experts who confirm the difficulty to distinguish between developmental delay or a real limitation.

The following information is collected:

– Diagnosis of impairment or illness lasting more than one year

- Participation in an early childhood care programme for developmental disorders
- Below age-appropriate level of physical or cognitive development

Limitations under investigation:

- Visual impairment (2-5 years)
- Hearing impairment (2-5 years)
- Difficulty in maintaining posture or walking (2-5 years)
- Difficulty in manipulating objects (2-5 years)
- Difficulty communicating with others (2-5 years)
- Difficulty in learning (2-5 years)
- Difficulty in expressing emotions and relating to other children (2-5 years)

For each limitation, the deficiency of origin is investigated

In relation to the care received as a result of the limitation, information is collected on:

- Assistance and personal care received
- Number of hours of assistance and/or care received
- Kinship relationship to caregivers

MAIN CARER QUESTIONNAIRE

The aim of the questionnaire is to obtain information about the main caregiver and the consequences of caregiving on aspects of their family life, work, leisure and recreation and on their health status.

- Socio-demographic information on the carer:
  - Age
  - Sex
  - Nationality
  - Civil status
  - Level of studies
  - Relationship to economic activity
- Information on the care provided:
  - Length of time providing care or assistance
  - Main tasks as a caregiver
  - Weekly days dedicated to the care of the disabled person or child with limitation
  - Hours per day dedicated to the care of the disabled person or child with limitation
  - Difficulties encountered in carrying out care tasks
- Implications for the life of the carer:
  - Implications of caregiving on health status

- Implications of caregiving on professional life
- Implications of caregiving on leisure, free time or family life

11 Processing of information

As the information is collected via electronic survey, the data is first cleaned using errors implemented in the application itself, which allows inconsistencies to be detected and provides strange value warnings when responses are being entered. In this way, the correction/confirmation of the information is carried out at the same time as the questionnaire is completed.

Once the information is available in the INE database, the processing and quality analysis of the received information begins. This processing consists of the following phases:

- *Coverage Phase*: It detects duplicates, compares the number of questionnaires theoretically collected (according to the computer application for monitoring fieldwork) and effectively received for each household.
- *Quality Control Phase*: It is verified that the information collected does not contain inconsistencies or serious errors used in the questionnaire.
- *Filtering and Imputation Phase:* Consists of detecting inconsistencies that have not been included in the electronic questionnaire, as well as obtaining marginal tables, variable analysis tables, etc. The correction of possible mismatched or lost values is carried out automatically and, where applicable, manually.

Once all the sample information has been collected and refined, it is aggregated and results are obtained according to the previously designed tabulation plan. To do this, several tasks are performed:

- *Calculation of raising factors and estimators*: Ratio estimators, to which reweighting techniques will be applied, will be used to estimate the sample's characteristics. Additional information used will depend on the characteristic under study.
- *Tabulation of the results*: According to the theoretic tabulation plan initially designed as per the survey objectives, the raised table are obtained using the calculated factors. These tables are refined by adding categories, eliminating or deleting cells from the final tabulation in those tables that do not have enough sample information to provide estimates with a minimum of statistical reliability.
- *Sample error calculation:* Variation coefficients will be calculated for the main variables studied and disaggregation. These tables will be published, along with the methodology, in order to replicate their calculation and be able to apply it to any other variable.
- *Non-response analysis*: a report is made with the basic characteristics of the units that did not collaborate in the survey.

12 Dissemination of results

The results of the Survey on Disabilities, Personal Autonomy and Situations of Dependency in Centre 2020 is published in April 2022 on the web page of the National Statistics Institute (www.ine.es).

When the data are released, users will be provided with the following publications:

(i) Statistics tables at the national and autonomous community level, distributed in 4 modules: Households, Disability, Limitations and Primary caregivers.

(ii) Sample error tables.

(iii) Analysis of non-response:

(iv) Methodological report.

(v) Questionnaires.

(vi) Anonymised microdata from the survey.

ANNEX I. GLOSSARY OF TERMS AND DEFINITIONS

Disability: Disability is understood, for the purposes of the survey, as any significant limitation in performing the usual activities of daily living that has lasted or is expected to last more than 1 year and is due to a disease(s) or health problem(s), and is estimated as such by the subject themselves. In this sense, it is considered that a person has a disability even though the limitations is overcome with the use or external technical aid or the aid or supervision of another person.

Impairment. These are problems in physiological functions (including mental functions) or body structures (organs or limbs) as a significant deviation or loss thereof. Impairment is related to deficiency or "lack of something". There are different types of impairment:

- Physical: an impairment that limits or impedes a person’s motor skill or functioning of their organs. The causes of physical disability may be from birth, or as a result of an accident (for example, a spinal cord injury), or a health problem (for example, a stroke).
- Psychological: these are mental health problems that involve difficulties in relationships with others or in adapting to society (for example, schizophrenia or bipolar disorder). This is commonly known as "Mental Illness".
- Sensory: the total or partial absence of hearing or seeing (blindness, deafness).
- Intellectual: problems in intellectual development that imply difficulties in understanding or learning at expected levels. This is commonly known as "Mental Retardation" and is frequent in people with Down syndrome, or Autism.
- Activity. Understood as the nature and functional performance of a person. Activities may be limited in their nature, duration and quality. An activity is considered severely limited when so determined by the subject themselves.

Usual activities. Regular activities include those related to the main activity (self-care tasks, housework, work, studies, volunteer activities, etc.) and those carried out in free time (socializing with friends, playing sports, attending shows, etc.).

Limitation of usual activities. Usual activities are considered limited when said limitation is due to illness or health problem(s), and when so determined by the subject themselves.

Technical aid is any external product or device used or intended for a person with a disability, which compensates or alleviates the limitation. For example: hearing aids, illuminated glasses, external prostheses, canes, wheelchairs, lifts, oxygen, cutlery with grip adaptations, access ramps, guide dogs, etc.

Personal aid is any collaboration from another person necessary to carry out an activity.

Supervision entails the need for a person to be aware of what another is doing, in case problems arise in a certain activity of daily life.

Medical consultation. Any visit to a licensed medical professional (in person or by telephone) for diagnosis, examination, treatment, follow-up, advice or any other procedure. Medical check-ups and requests for prescriptions are also considered to be medical consultations.

Collective medical examinations (work, school, etc.), the simple request for an appointment, consultations with a stomatologist, dentist or dental hygienist, the performance of any diagnostic test (X-rays, analyses, etc.) or therapeutic procedure indicated by a doctor, or contacts with pharmacists or opticians for the acquisition of medical prescriptions are not considered medical consultations.

Public Health (Social Security). A doctor is considered to be a Social Security doctor when he/she depends on the National Health System, which includes the former INSALUD, the health services of the Autonomous Communities and the rest of the public entities such as councils, provincial councils, local corporations.

Healthcare Company. This includes private healthcare companies (ASISA, ADESLAS, DKV, SANITAS, PREVIASA, etc.).

Private consultation. This is a consultation by a private doctor (a doctor who, in the free exercise of his/her profession, receives direct remuneration from the patient for the medical act).

Home healthcare. It is a service that aims to provide health care to a patient at home, when he/she cannot travel to a health centre or when it is considered that in this way a more humane care can be provided in a more suitable environment. It is usually developed mainly, but not exclusively, by primary care services.

Special home transport services. Health transport services are to be understood as. It is a service of a public, private or concerted nature that has the objective of transporting people or groups of people who are ill and/or injured, of greater or lesser severity, by means of vehicles specially prepared for this purpose within the route of the social and health infrastructure. It includes both urgent (ambulance) and non-urgent medical transport, and sometimes offers medical-health care en route. Also, the type of transport can be land, air or sea transport.

Telecare. Telecare is a service, aimed at elderly people who generally live alone or people with disabilities, which allows them to ask for help in case of an emergency, from their own home.

Home help. The Home Help Service consists of a set of preventive, training and rehabilitation actions carried out by qualified professionals in the home, with the aim of providing care for the basic activities of daily living required by the dependent person.

Psychosocial care for family members/Family support. Psychosocial care is defined as the set of articulated processes of services that have the purpose of favouring the recovery or mitigation of psychosocial damage, emotional suffering and impacts on the psychological and moral integrity and life project of families.

Day Centre/Night Centre service. These are specialised facilities where a group of professionals are dedicated to the prevention, treatment and care of the elderly and disabled. Day/night centres could be seen as the intermediate link between full independence for the elderly and residential care.

Temporary stays (respite services). Temporary stays are short stays in residential facilities, ranging from one weekend to several months, depending on the needs of the individual and his or her family. Other family respite stays of shorter duration correspond to weekends, long weekends or special dates such as, for example, Easter.

Housing or residential services. These are centres that offer comprehensive care and permanent housing to the elderly or people with disability, both those who can look after themselves and those in a situation of dependency who require help from another person to carry out the activities of daily living due to their health, family, social or economic problems.

Occupational centres. Occupational Centres are establishments whose purpose is to provide occupational therapy and personal and social adjustment services to people with disabilities, when they cannot find work in a company or access a special employment centre.

Other social services. These are services intended for the elderly or people with disability not previous covered, such as personal assistants, shelters, etc.

Contributory disability pensions. This is the income received by a person who, due to an accident or illness, will never be able to return to work or will be able to do so with limitations.

Non-contributory disability pensions. This is the money received by adults who have a high degree of disability, and who have paid very little or nothing to the Social Security (they have to be 65% or more disabled and, in addition to receiving money, they are entitled to medical and pharmaceutical assistance, etc.).

Financial allowances for having a dependent child with a disability. This is the extra money received by the parents of a child who has a disability of 33% or more. The money is received by parents or foster parents and continues to be received even if the child is over 18 years of age.

Economic dependency benefits. This is money a person receives when, due to some impairment, they need the aid of another person every day. Such economic benefits can be “PEVS” (economic benefits linked to service), when a private service is used because they cannot access a public one, and the “Benefit for care in the family environment and support for non-professional caregivers” which is granted to family caregivers until the third degree of kinship and at the time the benefits is applied for, they have been providing care for more than one year.

Other periodic monetary benefits. These are other economic benefits, such as the mobility allowance offered to people with disability who have severe difficulty using public transport.

Special Education Centre. These are schools or institutes that cater only for students with usually very severe disabilities. If non-disabled students attend, it is not a Special Education Centre. Special Education Centres can cater for students with any disability, or specialise in one type (e.g. deaf children, blind children, children with autism, etc.) Special Education Centres cater for students with disabilities generally up to the age of 21. From that age onwards, they are considered to be another type of non-educational establishment (although sometimes colloquially referred to as a "school", they are not).

Special education classroom in a mainstream school. These are classrooms that cater only for students with disabilities, but are within a school or institute attended by non-disabled students in other classrooms. The permanence of students with disabilities in these classrooms should be permanent or quasi-permanent. This should not be confused with one-off support classes for students with disabilities, but who are usually in the classroom with other students without disabilities.

Adaptation in their classroom or study centre. These are measures to facilitate students' access to and participation in education. It generally includes the removal of architectural barriers in doors, bathrooms, or classrooms, but also the installation of domotic or technological devices for the classroom station, or the monitoring of the class. Changes in the number of students, or changes in timetables or any other issues that facilitate the inclusion of the student in the classroom, but are not related to the learning content, can also be considered in this case.

Curricular adaptations. These are all the measures that are taken to facilitate that the student with a disability can acquire the basic learning competences that are established in the curriculum of the course or stage. It includes the adaptation of content, teaching methodologies or forms of assessment. It does not include devices or technologies for accessibility to spaces or content (these are considered adaptations of the centre or classroom).

Reserve quota for persons with disabilities. This is the obligation for public and private companies with 50 or more employees to reserve at least 2% of their jobs for workers with disabilities.

Selective access process (to public employment). This measure refers to the quota of vacancies that, in public employment offers, must be reserved so that they can be filled by people with disabilities. At present, at least seven percent of the places on offer must be reserved. Of these, at least two percent should be reserved for persons with intellectual disabilities, and the rest for persons with any other type of disability.

Specific contract for people with disabilities. It is a contract formalised in writing and in an official form that has a series of specific requirements relating to the worker (having a disability and being registered with the Public Employment Service, among others) and to the company (being up to date with their tax and Social Security obligations and not having been excluded from access to the benefits derived from the application of employment programmes due to the commission of very serious infringements that are not time-barred, among others).

The specific contract for people with disabilities can be indefinite, temporary, interim or for training and apprenticeship.

The signing of this contract gives the right to certain incentives that vary depending on the type of contract, the degree of disability, the age and sex of the worker and whether the contract is signed by an ordinary company or a Special Employment Centre (subsidy for the company for each contract signed, rebates on Social Security contributions, subsidy for the adaptation of the workplace, deduction in the Corporate Tax quota...). Likewise, the conversion of temporary contracts into permanent contracts is subsidised.

Work enclaves. A work enclave is understood to be a contract between a company in the ordinary labour market (collaborating company) and a Special Employment Centre (CEE), for the performance of works or services that are directly related to the main activity of the collaborating company and for the performance of which a group of disabled workers from the Special Employment Centre temporarily move to the work centre of the collaborating company.

In addition to being a formula for commercial relations between ordinary companies and CEE, it is also an instrument for the creation of employment for people with disabilities and their possible incorporation into the open market. It favours the transition from protected employment to ordinary employment and is incentivised with a subsidy for the company, if it hires people with severe disabilities indefinitely, as well as with bonuses on Social Security contributions, the amount of which varies according to the type of contract, the degree of disability and the age and sex of the worker.

Supported employment. Supported employment is understood as the set of individualised guidance and accompaniment actions in the workplace, provided by specialised job coaches, with the aim of facilitating the social and labour adaptation of disabled workers with special difficulties of labour insertion who are hired by a company in the ordinary labour market through an indefinite or fixed-term contract, for a minimum of six months. Subsidies are available to finance the labour and social security costs generated during the period of development of the Supported Employment project, derived from the hiring of job coaches.

Rebates in Social Security contributions and other hiring incentives. Rebates and reductions in social security contributions are deductions aimed at reducing companies' social security costs and promoting the access of certain groups to the labour market. They differ in that the reduction is financed from the Social Security budget, while the rebate is borne by the State through the budget of the State Public Employment Service.

There are reductions in Social Security contributions both for the hiring of people with disabilities as employees (in ordinary companies and in Special Employment Centres) and for people with disabilities who are self-employed.

Aid or subsidies for self-employment of people with disabilities (interest on loans, investment, ...) In addition to bonuses and reductions in Social Security contributions, there are various types of aid and subsidies to promote the self-employment of people with disabilities: for setting up as a self-employed worker, to reduce the interest on loans granted by financial institutions to set up as self-employed, for technical assistance and for training. People with disabilities can also apply for a lump sum payment of their unemployment benefit to finance their establishment as self-employed workers or as worker-members of cooperatives or worker-owned companies.

Other measures to maintain or secure current employment. This could include some of the measures, other than those listed above, from which Special Employment Centres (CEE) can benefit, such as subsidies to partially finance employment-generating projects (creation or expansion of CEE), subsidies for salary costs up to a maximum of 50% of the minimum inter-professional wage, subsidies aimed at balancing the budget of CEEs that are not-for-profit or have been declared of public utility or aid for professional activity support units within the framework of the Personal and Social Adjustment Services of CEEs.

Accessibility. Accessibility is the characteristic that objects, environments, places, buildings, transport, products, services, tools and devices must have to allows all people to understand and use them easily, in conditions of safety and comfort, and in the most efficient, autonomous and natural way possible.

Accessibility, therefore, refers to the degree or level to which any human being, regardless of his or her physical condition or cognitive faculties, can use a thing, enjoy a service or make use of an infrastructure.

Primary caregiver. The main caregiver is the person who assumes the daily care and support of the person with a disability and/or in a situation of dependency, as well as the greatest responsibility in caring for them.

ANNEX II. CLASSIFICATION OF OCCUPATIONS (CNO-2011)

00.	Military-related occupations
01.	Directors and managers
02.	Scientific and intellectual technicians and professionals
03.	Technicians; support professionals
04.	Accounting, administrative and other office employees
05.	Workers in catering, personal, protection and retail services
06.	Skilled agricultural, livestock, forestry and fishing sector workers
07.	Craftspersons and skilled workers in manufacturing industries and construction (except installation and machinery operators)
08.	Installation and machinery operators and assemblers
09.	Basic occupations
99.	Does not know / No reply

ANNEX III. CLASSIFICATION OF ACTIVITIES

CNAE 2019 to one digit:

1. Agriculture, livestock breeding, forestry and fishing
2. Industry
3. Construction
4. Wholesale and retail trade; repair of vehicles and motorcycles
5. Public Administration, Defence, Mandatory Social Security
6. Education
7. Social Services and Health Activities
8. Other Services activities
9. Does not know / No reply

ANNEX IV. CLASSIFICATION OF IMPAIRMENTS (PERSONS AGED 6 YEARS OR MORE)

- MENTAL IMPAIRMENTS
  - 11. Developmental delay
  - 12. Profound and severe intellectual deficiency
  - 13. Moderate intellectual deficiency
  - 14. Mild intellectual deficiency
  - 15. Borderline intelligence
  - 16. Dementia
  - 17. Mental illness
  - 18. Other mental disorders
- VISUAL IMPAIRMENTS
  - 21. Total blindness
  - 22. Poor vision
- HEARING IMPAIRMENTS
  - 31. Prelingual deafness
  - 32. Postlingual deafness
  - 33. Poor hearing
  - 34. Balance disorders
- LANGUAGE, SPEECH AND VOICE IMPAIRMENTS
  - 41. Muteness (not due to deafness)
  - 42. Difficult or incomprehensible speech
- OSTEOARTICULAR IMPAIRMENTS
  - 51. Head
  - 52. Spine
  - 53. Upper extremities
  - 54. Lower extremities
- NERVOUS SYSTEM IMPAIRMENTS
  - 61. Paralysis of an upper extremity
  - 62. Paralysis of a lower extremity
  - 63. Paraplegia
  - 64. Quadriplegia
  - 65. Disorders of movement coordination and/or muscle tone

  - 66. Other nervous system deficiencies
- VISCERAL IMPAIRMENTS
  - 71. Respiratory system
  - 72. Cardiovascular system
  - 73. Digestive system
  - 74. Genitourinary system
  - 75. Endocrine-metabolic system
  - 76. Hematopoietic system and immune system
- OTHER IMPAIRMENTS
  - 81. Skin
  - 82. Multiple impairments
  - 83. Impairments not classified elsewhere

ANNEX V. CLASSIFICATION OF IMPAIRMENTS (CHILDREN AGED 2 TO 5 YEARS)

01.	Mental impairments.
02.	Visual impairments.
03.	Hearing impairments.
04.	Language, speech and voice impairments
05.	Osteoarticular impairments.
05.1	Upper limbs
05.2	Lower limbs
05.3	Other osteoarticular impairments
06.	Nervous system impairments.
07.	Visceral impairments
08.	Other impairments

ANNEX VI. CLASSIFICATION OF AETIOLOGIES (ORIGIN OF THE IMPAIRMENT)