The INSEE survey on handicaps, disabilities, and dependency

Aims and organization

The first wave of the INSEE survey on handicaps, disabilities, and dependency (hereafter HDD) was carried out in late 1998. It covered a sample of about 15,000 people living in institutions even temporarily, as is the case with many people treated for mental illness. The institutions included homes for the elderly, homes for young and adult persons with disabilities, and psychiatric institutions. The same persons will be surveyed again in late 2000.

In addition, between 300,000 and 400,000 people living in private dwellings filled out a brief questionnaire on "daily life and health" in the March 1999 population census. Following this filtering operation, 20,000 respondents will be visited by an INSEE interviewer, once in late 1999 and again in late 2001.

Statistical processing has already begun and—given the wealth and detail of data collected—will probably continue well into the new decade.

The ten-year surveys on health and healthcare carried out by INSEE in association with CREDES[1] since 1960 focus on medical issues. Their purpose is twofold: (1) to measure the prevalence of diseases and, more generally, the causes of health impairments;[2] (2) to measure the type and frequency of preventive and curative treatment.

The HDD survey (in French: Handicaps-Incapacités-Dépendance [HID]) looks at the effects of health problems on people's physical integrity, daily living, and social relationships. The emphasis is on social issues rather than medical ones—specifically, the technical and human assistance needs, and the assistance actually provided. The survey paints a broader picture of the health field without overstepping its bounds.

This project—a first for France—is the result of an intensive cooperation since mid-1995 with leading research bodies in the fields concerned. The project task force comprised researchers from CREDES, CTNERHI, FFP, INED, and INSERM, as well as MIRE and SESSI staffers representing the Ministry of Employment and Solidarity.[3]

The survey is largely financed by INSEE with contributions from many players in the assistance system for the handicapped and the elderly: the Ministry of Employment and Solidarity, the association in charge of managing the handicapped workers' integration fund (AGEFIPH), the national social-security funds (CNAMTS, CNAV, CNAF, and CANAM), mutual insurance organizations and insurance companies

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[1] For a full list of abbreviations used in this article, with the complete names in French and their English equivalents, see p. XX.

[2] In epidemiology, "prevalence" is defined as the proportion of cases of a given pathological condition at any one time in the population studied. It is classically distinguished from incidence, which is the proportion of people contracting the condition(s) in question over a specified period of time. Basically, this is the time-honored distinction between stocks and flows.

[3] SESI and MIRE were merged into a new Ministry Directorate (DREES), established by French government decree no. 98-1079 of November 30, 1998.

(FFSA, GEMA, and MGEN), supplementary-pension funds (AGIRC and ARRCO), and the French Association for the Paralyzed (APF).

This all-out participation came in response to the repeated demands from the National Council for Statistical Information (CNIS).[4] There was also support from the Interministerial Delegation for the Handicapped, and an endorsement by community groups for the disabled and their families and friends, in particular via their liaison committee.

From diseases to handicaps: the Wood sequence

The development of studies and statistics on handicaps is a relatively recent phenomenon. The International Classification of Diseases (ICD) was first published over a century ago and is now in its tenth revision. Yet it was not until 1980 that the British expert Philip Wood put together an "International Classification of Impairments, Disabilities, and Handicaps" (ICIDH) for the World Health Organization (WHO). The ICIDH was officially adopted in May 1988 by the French Ministry of Social Affairs.

Experts in these fields have since taken to describing the relationships between diseases and handicaps in terms of the "Wood sequence," which can be summed up as follows:

disease
↓
impairment
↓
disability
↓
disadvantage (handicap)

• **Diseases** (in the broad sense, i.e., including accidents and other mental and physical traumas) are the first link in the chain. They are susceptible to diagnosis and medical treatment.

• **Impairments** denote any loss (such as amputation or sclerosis) or dysfunction of a body part (limb, muscle or organ) or of the brain. They generally result from a disease or trauma. A similar and more commonly used notion is "invalidity."

• **Disabilities** are a restricted ability, or a lack of ability, to perform normal activities or more complex ones. Normal activities include physical activities such as standing up, getting up, or walking up a staircase, and mental activities such as memorizing. Complex activities include dressing, using the telephone, and conversing with several persons. Disabilities are generally due to one or more impairments.

• **Disadvantages** is preferred by French-speaking specialists to the English "handicaps." Disadvantages denote a restricted ability, or a lack of ability, to fulfill a social role that the person may seek to perform or that society expects of the person. Such roles include attending school, doing work, communicating with other people,

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[4] In its general recommendations for the 1996, 1997, and 1998 official statistical programs.

and parenting. They are situated at the crossroads between the natural and social environment and the person’s individual characteristics. For example, persons confined to wheelchairs may not be disadvantaged in terms of employment if the transportation to their workplace is easily accessible to them, and if they have no significant impediment in using a specially equipped workstation. Obviously, people who are still fully mobile will not suffer from disadvantages in employment either, even if the transportation is inconvenient and if their workstation is located, for example, at the top of a crane (unless other health problems, such as chronic vertigo or an intellectual impairment, make urban travel or working in an uncomfortable position difficult). A disadvantage in a given field—here, employment—is therefore the product of (1) a personal situation, such as the paralysis of lower limbs, and (2) environmental conditions, such as user-friendly transportation and a suitable workstation.

For social and health policy, this is a useful way to describe problems, since it reveals a range of possible actions to reduce the handicap:

- medical research and healthcare to cure or prevent the disease;
- development and provision of prosthetics to reduce an impairment;
- distribution of technical and/or human assistance with daily tasks (for example: specially designed bathtubs for the aged; a nurse to help with washing and dressing in the morning);
- environmental action (such as improvements in street fixtures, transportation, and workstations).

A multi-purpose survey

The HDD project has four main goals: (1) to provide framework data, (2) to establish forecasts and estimate flows, (3) to make the most of existing sources, and (4) to meet local players' information needs.

The first objective required a survey of both the institutional population and private households. The second required tracking the survey respondents over time. This called for two surveys—each with its tracking procedure—and even three surveys, since the definition of the HDD survey sample of private households demanded a prior large-scale filtering of the total population using the criteria of the Daily Life and Health survey (hereafter DLH; in French, Vie Quotidienne et Santé: VQS).

The questionnaire also had to contain a clear summary of the many evaluation grids for disabilities and handicaps. As regards the satisfaction of local needs, the main approach used was to develop methods for estimating results in each *département* from the national figures.

Providing framework data

A remarkable report from the CNIS ad-hoc working party (1997) showed the paradoxical situation concerning information on handicaps and dependency in France.

The financial impact of handicaps and dependency on the social-security accounts is massive: for 1995, CNIS estimated it at FRF180 billion. A large number of players—many of whom wield considerable power—define the information needs and provide the funds to satisfy them. In addition, the aging of the French population is prompting fears of a heavier financial burden. Yet even a superficial glance reveals a conspicuous absence of any reliable, comprehensive evaluation of the population concerned.

This is not because of a lack of information. On the contrary, a wide variety of information is available in the form of local surveys and industry statistics produced and funded by one or other of the many systems in charge of assistance and official recognition of disabilities. However, there is no guarantee that all these independent sources, collection methods, and evaluation grids—with their partial and often non-comparable figures—cover all possible situations.

That is why the priority of the INSEE survey was to provide framework data covering the entire population.[5] The aim is neither to replace existing sources nor to match all their qualities, but to overcome their major deficiency by supplying an overall picture. Central government and local authorities alike require comprehensive data to assess the volume of assistance needs. The other players—typically specialized in assistance to a particular sub-group—expect to have data on their own sector as well as the opportunity to see where they stand as part of the whole.

Preparing forecasts and estimating flows

Policy-making in the area of handicaps and dependency obviously requires forecasts. This is especially true at a time when demographers are projecting a massive rise in the number of seniors—particularly in the oldest age groups—over the coming decades.

However, basing these forecasts on the combination of demographic projections and the prevalence of handicaps at each age would produce highly erroneous and utterly pessimistic findings. In reality, the French population's state of health is improving constantly, so the proportion of handicapped persons at each age is falling sharply.

For example, the number of people who have become disabled has fallen sharply in recent decades thanks to better living conditions and progress in the medical treatment of disabling conditions—primarily cardiovascular diseases and osteoarthritis.

This trend does is not confined to seniors. One of the many examples among "middle-aged" adults concerns paraplegics: many are victims of polio, a disease that has been eradicated in France.

Stock data derived from often old and inconsistent entry-flow data are therefore unsuitable for forecasting numbers and needs. They can even be misleading. Forecasting requires an assessment of today's flows. This is precisely the principle of

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[5] The French overseas *départements* are not included in the survey in progress, since suitable questionnaires need to be drawn up for them.

demographic forecasts, which are based on the measurement of current age-specific death rates and their changes.

The HDD survey accordingly places strong emphasis on evaluating the two types of flow: entry flows into disability or dependency, and exit flows through death or recovery. Three concurrent techniques are planned for this purpose: retrospective questions, two repeat visits to analyze the changes in individual situations (remissions and aggravations), and a specific evaluation of mortality.

Another gain expected from these results is an improvement in the disability-free life expectancy (DFLE) tables. These tables were put together following the 1980 health survey for the more general development of a summary indicator of the French population’s state of health (and changes therein). They are widely used by insurance companies, mutual insurance organizations, and pension funds as a basis for computing disability-insurance premiums and benefits.

Making the most of existing sources

One of the consequences of the information patchwork generated by a highly fragmented assistance mechanism is the proliferation of methods for measuring handicaps and disabilities.

In 1983, the École Nationale de Santé Publique in Rennes (a public-health training institution) conducted a survey of dependency evaluation grids for the elderly. The inquiry—whose main focus was on France—enumerated and analyzed more than 150 different grids. All of them were actually used in one way or another, especially in institutions, and many had been applied in field surveys. This gives an idea of the unrelenting stream of research projects on the topic since the 1980s.

Another, more recent example is that an individual may be assigned up to four or five different disability or invalidity rates by the social-security system, the COTOREPs, insurance companies, the army, and other organizations.

The basic principle adopted at the very start of the HDD project definition stage was to avoid creating a new evaluation grid for disabilities and handicaps that claimed to be better than all the existing ones. Rather, we chose... not to choose any particular grid over the others.

The project group accordingly pursued two objectives:

- To decide which grids should be taken into account. This was done by dissecting their individual items to arrive at the "smallest common denominator" so that the main national and international players could compare their findings with those of the survey under construction.
- To produce an equivalent, in survey-questionnaire form, of the AGGIR procedure, which is becoming the chief method for evaluating seniors. In particular, it has been adopted as the guideline for allocation of the special dependency benefit (Prestation Spécifique Dépendance: PSD).

The field tests for AGGIR procedure simulation by statistical questionnaire were successful. Because this procedure was initially the most complex, we believe the project will indeed be able to meet its prime goal, i.e., to produce framework data compatible with the main grids and procedures used in France and those recommended by international organizations.

Satisfying local players' information needs

The fourth goal—which obviously extends beyond information on handicaps—is typically frustrated by cost barriers. It is impossible to obtain even a minimum of reliable information from a statistical survey with a sample of fewer than 2,000 people (or 2,000 households, if the survey was on household characteristics). In the case of the ten-year health surveys, for example, nearly 200,000 people would have to be interviewed to obtain information at the *département* level. That would be the most relevant echelon in the current structure of French health-policy management: local powers are vested in the *département*'s elected body, the *conseil général*. The sample would be ten times larger than the one used in the national surveys—and ten times as expensive.

Yet local entities—such as local authorities and community groups—play an essential role in assisting handicapped and dependent persons. Satisfying their information needs was therefore one of the priorities of the household section in the HDD survey.

Since a massive extension of the sample was out of the question, other alternatives had to be explored. Most efforts went into developing methods for estimating *département* results from the national survey.

The working principle was to use information from other sources available at the targeted geographic level to "rectify" the national results through ratio adjustments[6] and "small-area estimates."[7]

All that was needed for the survey of the institutional population was a simple ratio adjustment to the total numbers of institutions and residents/patients in each *département*.[8]

Ratio adjustment will also be required for private households. The reference here will be the demographic and social structures of the *département* determined from the population census.[9] The frequency, type, and severity of handicaps are known to depend rather heavily on age and gender. They are also linked to the respondent's

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[6] Question pour l'auteur: il me semble que ce terme correspond à "calage aux marges" mais nous pouvons en reparler ensemble.

[7] For the past several years, the international statistical community has been developing concepts and acquiring experience in the estimation of small areas. The U.S. National Commission on Health Statistics (NHCS), for example, has produced figures at county level from its National Health Information Survey (NIHS), which interviews some 100,000 people every year.

[8] Source: SESE-DREES. The survey covered a total of 11,500 institutions with about 650,000 residents. Slightly more than one in six institutions (2,075) and eight residents per institution were selected for the national sample.

[9] The timetable is conducive to this, since the March 1999 census figures will be available by then.

life history (living conditions and working conditions), which is customarily summed up in the notion of "social class."

Stopping there, however, would mean assuming that no other factors influence the frequency of handicaps. The little historical evidence available suggests that such a hypothesis is extremely simplistic. For example, the 1851 census included a count of individuals suffering from goiter, including "goitrous cretins." It found a very uneven geographic distribution, which gave support to the assumption that salt and iodine deficiencies in the diet were key determinants.

This illustrates the need for information more directly related to the survey's subject in order to refine the *département* estimates. However, we knew that sufficiently homogeneous national data bases would not be available. Let us take just one example: the decisions by the COTOREPs to recognize a handicap (an adult handicap, which creates eligibility for the adult handicapped allowance; or a geriatric handicap, which creates eligibility of the special dependency benefit). The number of decisions is extremely variable from one *département* to another, and seems too closely related to the disparity of local policies on these issues. We therefore decided to make do with the figures from the Daily Life and Health survey, which will serve three purposes: (1) to enumerate the handicapped and dependent population living in private dwellings; (2) to provide a basis for defining the HDD survey sample; (3) to provide a basis, in addition to the population census, for estimating HDD household figures for each *département*.

We will look at the principles and organization of the DLH survey in detail later. The point worth noting here is that we were able to extend the survey to *département* samples at a reasonable cost (FRF200,000 on average).

There was considerable support for the resulting arrangements, i.e., a rectification of the HDD household results at *département* level using the population census and the DLH survey, with the possibility of extending the DLH sample. The authorities of one *département* (the Hérault) opted for a complete extension, i.e., DLH survey + HDD survey of private households.[10] This will give the authorities results taken directly from a local survey rather than solely from estimates, however sophisticated they may be.

The survey must cover institutions and private dwellings

The most obvious practical consequence of the HDD project's goals was the need to survey both the private-household population and the institutional population.

The institutional situation was clearcut. The largest entities specifically consist of healthcare and welfare institutions accommodating handicapped persons and seniors suffering from functional impairments.

This category primarily includes homes for seniors and handicapped adults, teenagers, and pre-teenage children.

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[10] Under the terms of the extension agreement reached with the Hérault *département*, an extra 1,800 people were added to the 20,000 making up the national sample.

We added psychiatric institutions even though they provide care rather than accommodation. The reason for our choice is that psychiatric patients often suffer from impairments or disabilities as well. Also, the stays in these institutions are often so long that we would have been unable to find such patients in the section of the survey that covers private dwellings.

Many sample surveys and even complete surveys have been conducted on these institutions on a nationwide scale, but most of them concentrate on operational aspects. Their questions on the characteristics and needs of residents/patients tend to be rather limited, and vary from one type of institution to another.

The need for a survey of private dwellings was perhaps even more urgent. First, all the evidence available suggests that most handicapped and dependent people live at home. Second, the information available comes from highly scattered, incomplete, and methodologically diverse sources. Third, there has been an extension of the policy to enable the elderly and the disabled to continue living at home: this has further increased the percentage of seniors and disabled persons in private dwellings.

For practical reasons, we decided to interview some 15,000 people living in institutions. The private-dwelling survey was to cover about 20,000 people—a sample roughly equal to the one used in the ten-year surveys of health and medical care.

Specific surveys are also being planned for population categories not covered by these two main sections, such as the homeless.

Counting and describing: two separate stages for individuals living at home

Surveys on handicaps and disabilities must satisfy two basic requirements: enumerating the people concerned (or assessing their proportion in the total population), and describing their situation.

A high percentage of the residents and patients in institutions for the handicapped and seniors, and in psychiatric institutions, fall within the scope of the study. The two tasks can thus be performed in a single operation without significant waste.

This is not the case for people living in private dwellings, who—as indicated earlier—form the overwhelming majority of the handicapped and dependent population. They require a two-stage survey, as recommended, for example, by a recent UN-Stat manual. The first stage serves merely to count the people concerned and select those for subsequent interview. It is called the filtering stage. The second stage serves to describe respondents' disabilities, the origins or causes of these disabilities, and any limiting consequences on participation in the main areas of social activity.

The first stage can obviously be dispensed with if a national census data base is already available on handicapped persons, from which a sample can be drawn for the second stage. No such base exists in France, since each assistance or insurance system maintains its own. (Major examples are COTOREP and CDES among the assistance systems, and the records for industrial accidents and disabled war veterans in the insurance sector.)

Basing our sample on existing data bases would consequently have meant:

- Accepting double counts, which statisticians dread. To avoid the issue would have required a painstaking matching operation, but this would have been problematic because of the precautionary measures stipulated in the Information Technology and Civil Liberties Act. INSEE had no desire to pursue such an approach.
- Accepting, in principle, the notion that the assistance system matched assistance needs, at least in quantitative terms. But experts consulted on this matter were unanimous: there is no way of guaranteeing this.

We therefore reached the clear conclusion that the only way to filter was to conduct a preliminary survey of a vast sample of the total population.

Choice of a filtering survey complementing the population census

A filtering survey requires a sample eight to ten times larger than the population to be interviewed and described. The sample for the HDD survey’s household section was set at 20,000 people. The preliminary filtering operation—i.e., the Daily Life and Health survey—thus had to cover at least 160,000 people representative of the French population living in private dwellings.

All the possible ways of carrying out a survey of this size were carefully considered.

We decided against a postal survey, even though this is generally a low-cost method. The response rates are low and, in this case, there was a risk that non-responses would be due to the very phenomena we were attempting to survey. The resulting response sample would not have been representative of the field of study.

Initially, therefore, we estimated the respective costs and pros and cons of an area survey and a telephone survey, on the basis of a projected sample of 200,000 people. The advantage of the area survey was that it could be entirely handled by INSEE's network of interviewers.[11] However, training and paying the interviewers would have cost about FRF7 million. The telephone survey would have had to be outsourced to an independent private-sector company, since the Institute currently lacks the resources needed to handle an operation of such size. The cost of this alternative was also estimated at around FRF7 million, not counting the cost of the lists of names, addresses, and telephones.

Cheaper solutions had to be found.

The area-survey option chosen was not, strictly speaking, a survey by interviewers. It consisted in adding the DLH survey to the March 1999 population census.

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[11] See Françoise Dusset, "Le réseau d'enquêteurs de l'INSEE: 50 ans d'histoire," *Courrier des statistiques*, no. 78, August 1996.

The collection cost was brought down to FRF1.4 million without reducing the 200,000-person sample. This huge saving allowed the extension of the national DLH survey to nearly 300,000 people. The sample-definition method for the HDD survey in private dwellings was thus consistent with the standard random-draw procedure for census-based sampling, including for those strata assumed to consist of tiny minorities of the population.

The second advantage was that extension agreements were reached with eight local authorities that had expressed an interest in the option. As a result, the total DLH survey sample was increased to about 400,000. What would have been virtually impossible with the small network of INSEE interviewers now became feasible with the help of census enumerators.

Furthermore, the incorporation of questions on daily life and health into the census schedule satisfied long-standing, repeated demands that echoed UN recommendations (it will be noted that the French census already contained questions on a number of disabilities for the entire population).[12]

In practice, a representative sample of census districts was selected (between one in 200 and one in 150). Along with the standard census forms, enumerators in these districts will give households an additional, three-page DLH questionnaire containing 18 headings, each divided into four individual columns. Households with more than four members will be given supplementary forms.

The DLH questionnaires will be filled out by the relevant individuals or their next of kin. Enumerators will assist or advise only if asked—a procedure referred to as the distribution-collection method.[13]

A few months later, the respondents selected on the basis of DLH questions will be visited by INSEE interviewers, who will carry out the actual HDD survey.

Constructing a well thought-out sample

In designing the DLH survey, we drew on Statistics Canada's experience in the 1986 and 1991 population censuses, when it conducted a preliminary selection ahead of its Health and Activity Limitation Surveys (HALSs). The Canadian agency introduced two general questions into the census schedule for one-fifth of the population. The questions were intended to screen for individuals suffering from activity limitations due to health problems.

The results revealed the shortcomings of an overly summary filtering technique. Admittedly, one one-tenth of the people described by this procedure as "limited" were found to be false positives in the detailed HALS. However, when the HALS

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[12] The 1996 UN *Manual for the Development of Statistical Information for Disability Programmes and Policies* states that 19 national censuses undertaken in the 1980s included questions on handicaps.

[13] Having respondents fill out additional forms on their own is a standard procedure in France: it is already employed in the "Family" survey (see the article by F. Héran, L. Toulemon, and F. Cassan in this issue). The samples for the DLH and Family surveys were obviously drawn in a coordinated manner to avoid selecting the same households for both surveys.

questionnaire was put to a control sample of persons not screened as "limited," over one-third of all targets were shown to have slipped through the filter.

While it is obviously easier to analyze the situation with hindsight, this relative failure is not surprising. Having a handicap or being handicapped is not a discrete characteristic that can serve as an unambiguous dividing-line between two sub-groups. Most of the handicap-evaluation grids classify individuals on a quantified scale comprising a fairly large number of levels. A yes/no separation cannot be made until the administrative-recognition stage, i.e., when the person is ruled eligible for an allowance, a disability card, or a place in a special educational institution, sheltered workshop, or home. Here again, the disability rates range on a continuous scale from 0% to 100%.

We therefore had to make adjustments to the Statistics Canada method. The first was to prepare a set of wide-ranging, largely factual questions based on ad-hoc filtering experience—rather than one or two general, catch-all questions that would inevitably have been interpreted in different ways.

We also dropped the idea of a "mandatory sorting" of positives from negatives when putting together the second-stage sample. In determining the HDD survey sample of private households, we therefore used the DLH responses to define population categories characterized by different probabilities or severities of the presumed handicaps. Each of the resulting groups will be allocated a specific sampling coefficient, which will increase with the probability or severity of the presumed handicap.[14]

Persons belonging to the most definitely and severely handicapped group will have a high sampling rate. Those belonging to the group whose answers indicate no daily-living problem or restriction (the largest group) will have a minimum sampling rate. All these coefficients will then be adjusted to obtain a total of 20,000 people.

This construction method has several advantages.[15] First, the sample strongly over-represents persons suffering from a handicap. Second, the different levels of handicap are represented, so that it will be possible to extract data irrespective of the various administrative-recognition thresholds. Third, the inclusion of moderately handicapped persons will be particularly valuable for preparing a second survey wave to shed light on handicap evolution phenomena.

This preliminary-filtering arrangement could probably be applied to other surveys of minority sub-groups, which are hard to identify from census data or other sampling frames.

Evaluating a disadvantage

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[14] The detailed survey findings will be used to evaluate the ranking errors, i.e., the over- or underestimation of the existence and severity of the handicap.

[15] This is, in essence, a classic stratified sample. The only distinctive feature is that the stratification variable is determined by a prior survey of a much larger sample, which acts as a sampling frame for the full survey.

The HDD survey covers the three levels of handicap defined at the beginning of this article: impairment, disability, and disadvantage. The third level, disadvantage, is comparative. In employment, for example, identifying or measuring a given disadvantage does not merely consist in establishing that X% of deaf or blind males aged 30-35 cannot find work. This rate needs to be compared with the average unemployment rate among men of the same age.

In the world of statistical surveys, however, comparison means a risk of bias. If the figures available are collected from different questionnaires, there is no way to be sure that their differences reflect a genuine diversity of situations rather than an artificial one. The most common method used to minimize this risk is to introduce a reference population into the interviewed sample. The population has to be large enough to ensure that the results concerning it can serve as a basis for comparison.

The obvious drawback is that the survey's target population—here, persons suffering from restrictions of varying severity due to a health problem—is reduced by the size of the reference population.

We therefore chose a different procedure. The questions on disadvantages include core questions for each of the topics addressed: housing, transportation, schooling, employment, income, leisure, and social relationships. This core is drawn and reproduced as faithfully as possible from the corresponding specialized INSEE survey. The reference population for each topic, therefore, consists of the sample used in the specialized survey on that topic.

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dictionnaire p. 8
(NB: on doit arriver à faire tenir la présentation bilingue sur une seule page en jouant sur la taille des caractères dans les deux langues)

Abbreviations used in this article

AAH	Allocation aux Adultes Handicapés *Handicapped adult allowance*
AGEFIPH	Association Nationale pour la Gestion du Fonds d'Insertion Professionnelle des Personnes Handicapées *National association for the management of the handicapped workers' integration fund*
AGGIR	Autonomie Gérontologique Groupes Iso-Ressources *Isoresources group to measure seniors' independence*
AGIRC	Association Générale des Institutions de Retraites des Cadres *Association of supplementary-pension organizations for management-level workers*
APF	Association des Paralysés de France *French association for the paralyzed*

ARRCO	Association des Régimes de Retraite Complémentaires des Salariés du Régime Général *Association of supplementary-pension systems for payroll workers covered by the general social-insurance plan*
CANAM	Caisse Nationale d'Assurance Maladie des Professions Indépendantes (*also known as* CNAMPI) *National sickness-insurance fund for the self-employed*
CDES	Commission Départementale d'Éducation Spéciale *Commission on special education (i.e., for pupils with disabilities) in the* département
CNAF	Caisse Nationale des Allocations Familiales *National family-allowance fund*
CNAMTS	Caisse Nationale de l'Assurance Maladie des Travailleurs Salariés *National sickness-insurance fund for payroll workers*
CNAV	Caisse Nationale d'Assurance Vieillesse *National old-age pension fund*
CNIL	Commission Nationale de l'Informatique et des Libertés *National commission on information technology and civil liberties*
CNIS	Conseil National de l'Information Statistique *National council on statistical information*
COTOREP	Commission Technique d'Orientation ou de Reclassement Professionnel *Technical commission for occupational guidance and rehabilitation of the handicapped*
CREDES	Centre de Recherches, d'Études et de Documentation en Économie de la Santé *Center for health-economics research, studies, and documentation*
CTNERHI	Centre Technique National d'Études et de Recherches sur le Handicap et l'Inadaptation *National technical center for studies and research on handicaps and maladjustment (founded and supported by INSERM [q.v.] and the Welfare Program Directorate of the Ministry of Employment and Solidarity, it works in close partnership with non-profit organizations for the handicapped)*
DFLE	*Disability-Free Life Expectancy*
DLH	*Daily Life and Health: INSEE survey described in this article (French: VQS)*
DREES	Direction de la Recherche, des Études, de l'Évaluation et des Statistiques *Directorate for research, studies, evaluation, and statistics (Ministry of Employment and Solidarity)*
FFP	Fédération Française de Psychiatrie *French psychiatric federation (includes all psychiatric societies)*
FFSA	Fédération Française des Sociétés d'Assurance *French federation of insurance companies*
GEMA	Groupement des Entreprises Mutuelles d'Assurances *Association of French mutual-insurance organizations*
HALS	*Health and Activity Limitation Survey (Statistics Canada) (French: ESLA)*

HDD	*Handicaps-Disabilities-Dependency: INSEE survey described in this article (French: HID)*
HID	Handicaps-Incapacités-Dépendance: *see HDD*
ICD	*International Classification of Diseases*
ICIDH	*International Classification of Impairments, Disabilities, and Handicaps*
INED	Institut National d'Études Démographiques *National institute of demographic studies*
INSEE	Institut National de la Statistique et des Études Économiques *National institute of statistics and economic studies*
INSERM	Institut National de la Santé et de la Recherche Médicale *National institute of health and medical research*
MGEN	Mutuelle Générale de l'Éducation Nationale *Mutual insurance organization for teachers*
MIRE	Mission de Recherches *Research unit, Ministry of Employment and Solidarity*
NCHS	*National Center for Health Statistics (U.S.)*
NIHS	*National Health Interview Survey (by NCHS)*
PSD	Prestation Spécifique Dépendance *Special dependency benefit for seniors*
SESI	Service des Études et des Systèmes d'Information *Department of studies and information systems, Ministry of Employment and Solidarity*
VQS	Vie Quotidienne et Santé: *see DLH*
WHO	*World Health Organization*

encadré p. 10

Age, handicaps, and dependency

Why conduct a single survey on handicaps and dependency? "Handicap" is a term usually applied to children and adults of working age. "Dependency," by contrast, is a term generally applied to seniors, as illustrated by the name given to the recently introduced "special dependency benefit" (Prestation Spécifique Dépendance: PSD).

One of the main reasons for the consolidation is that, far from being natural and unchanging, age boundaries—for example, between seniors and working-age adults—are a social product that can change quickly.

In the ICIDH, age is included only in the third level of handicaps (i.e., disadvantages). In other words, age is a factor only as regards the social roles to which the person may aspire, or the roles that society expects the person to play.

Breaks may be introduced, such as those associated with schooling and retirement, but the resulting age limits are socially defined and change over time. For example, employment introduces the only clear break between a "handicap age" and a "dependency age." Yet retirement age is subject to change and varies with occupation. Moreover, a person hitherto described as handicapped who stops working will not necessarily be reclassified as dependent—a shift that could occur when the handicap was evident only in the workplace.

In sum, there is no age limit as such. There are only social limits—which are diverse and temporary.

encadré p. 11

Three concurrent ways to measure flows

The questions on disabilities include a question on how long each stated restriction has been experienced. Tests show that responses are almost always obtained on this point and that they are of fairly good quality.

The survey will comprise two visits, at a two-year interval, to institutional residents and persons living in private dwellings. The procedure will make it possible to analyze the positive or negative change in individual situations on the disability severity scale. This is an area where information is particularly scarce today. For example, who can assess "remission" flows—i.e., returns to independence or non-disability situations—with any accuracy? Yet we do know with certainty that the number of remissions is not, or is no longer, insignificant. One obvious example is cataracts. So many cataract sufferers used to be confined to their homes, virtually blind. Today, cataracts are treated by surgery, with remarkable success.

Lastly, estimates will be made of mortality by type of impairment and severity of handicap. In this field as well, information is scarce. There is a widely held belief that mortality is higher than average among the handicapped in general, or at least for certain types of handicap. Yet we have no quantitative evaluations to prove this. The two-year interval will probably be too short to obtain sufficiently robust findings, quite simply because the sample size means that the number of deaths will be rather small. The project group is therefore considering longer-term tracking based on death certificates for the sample surveyed. Under the same approach, it would be particularly useful for public-health policy-makers to be able to compare the types of impairments covered by the survey with INSERM's information on causes of death.

encadré p. 12

AGGIR

The AGGIR procedure measures the independence of seniors (over 60 years old) against six "isoresources" groups.[1] The groups are numbered from 1 to 6 by decreasing level of dependency. Group 1 mainly comprises individuals who have lost their mental, bodily, motor, and social independence, and thus require a continuous presence of caregivers. At the other end of the scale, Group 6 is composed of people who remain independent in all daily-living activities, such as eating, dressing, washing, urinary and fecal elimination hygiene, getting around, orientation in time and space, using means of communication, and rational behavior.

The measurement is made by a team of doctors and social-services professionals, who interview individuals about their state of health, the activities they can perform, and their environment. The team then fills in an assessment grid, which is processed by a software program that determines the respondent’s isoresources group.

The project group developed a set of questions for the HDD survey form to "emulate" the AGGIR evaluation method. The resulting questionnaire was tested on a group of AGGIR-procedure participants. The individual results were compared and the emulation was found to be highly satisfactory. As a result, the "AGGIR questions" were incorporated into the HDD questionnaire.

1. An "isoresources" group is a group of people requiring a comparable volume of assistance, measured in man-hours.

encadré p. 13

Most dependent people live in private dwellings

Dependency is more frequent in the institutional population, because it is one of the main reasons for entry, and because that population is much older. Yet the majority of dependent people live at home.

Estimates based on several regional surveys from the 1980s show that only 23% of bed-ridden and chair-ridden persons over 65 years old lived in institutions. The proportion of institutional residents dropped sharply for less severe dependency. SESI estimates in the early 1990s found much higher percentages, with one-third of highly dependent seniors living in institutions. The consensus, however, is that most dependent people live at home.

This phenomenon explains the pervasiveness of "informal" care, usually provided by the family.[1] Now one of the features of informal care is the lack of official registration, hence the absence of any informational by-product. This clearly confirms the need for an information system that extends beyond the professional sector.

1. Informal care is generally taken to mean any care not directly provided by a professional sector—i.e., a medical, social-service, or institutional sector. Informal care thus includes services provided by professionals and volunteers working for non-profit organizations.

encadré p. 14

Complementary surveys

Many groups living outside institutions and private dwellings are also liable to suffer from specific, illness-induced problems.

Four notable categories are: students living in university residences, which offer accommodation specially equipped for the handicapped; members of religious orders, who are often elderly, and reside in monastic institutions; prisoners; and the homeless. Because of its distinctive features, each group requires special collection methods.

Over the next two years, INSEE is planning to conduct a national survey of the homeless, which will include summary HDD questions. Special surveys will be needed for the other population groups, probably in association with the relevant institutions.

biblio . 16

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