Pascal Roussel:
The French survey "Handicaps, Incapacités, Dépendance" (HID) in institutional settings
The French survey *Handicaps, Incapacités, Dépendance*¹ (HID) in institutional settings
Centre Technique National d’Etudes et de Recherches sur les Handicaps et les Inadaptations²
WHO French collaborating center for ICF

The French survey HID in institutional settings is a component of a larger survey on disability which has been conducted by the National Institute on Statistics and Economical Studies (INSEE) both in institutional settings and in households.

**Main aims of the HID survey**

The main aims of this survey are:
- to evaluate the number of persons who experience disability in France, whatever the level of this disability is, wherever people live, and whatever their age, administrative and social status;
- to describe the components of the disability (including the social dimension) and the physical and social environment in which the persons live³;
- to describe the impact of disability in terms of burden for the eventual caregivers, and in terms of needs for different kinds of assistance;
- to draw projections about disability in the future;
- to meet the needs for grounded information for local policies;

Because of this multidimensional approach, it was decided that the questionnaire would be based on the version of ICIDH current in 1995: ICIDH-1.

These aims led INSEE to collect data about two groups:
- the persons who live in ordinary settings (households); previous data estimated that 2/3 or 3/4 of persons with « severe » disability lived at home;

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¹ The title of this survey may be translated as « Handicaps, disabilities and dependancy »
² CTNERHI 236 bis rue de Tolbiac 75013 Paris France
³ The description of disability should allow the evaluation of disability based on any of the usual dependancy grid used in France or recommended by international organism ;
- the persons who live in institutional settings (and specially in what is considered as « medico-social » institutions in France).

This procedure required three different surveys:

- an institution survey
- a screening survey linked to the national census for persons living in ordinary settings (households)
- a household survey based, for sampling, on the result of the screening survey.

Two of those (in institutions and households) were conducted twice at a two years interval in order to estimate the disability entry and exit flows.

The preliminary work of the data collection began in 1995 and the data collection is still going on. The Institution Surveys were conducted in 1998 and 2000. The first Household Survey was conducted in 1999; the second one is in progress.

This paper reports the methodology and some of the main results of the 1999 Institution Survey.

**Inclusion criteria**

As the HID survey intends to make a census of people with disabilities in France, the institutions included in the survey ought to be all those in which people live when they do not live in private households.

For technical reasons, some of them where not included in HID survey: jails (which are the object of a specific investigation based on a very similar questionnaire to the one used in other institutions), convents, middle and long term medical residences, boarding schools and colleges. Moreover the data for people living in the streets have been collected through a couple of questions included in a special survey concerning the life conditions of this specific population. People living in French overseas territories were not included.

In brief, the institutions included in HID surveys are:

- institutions for youth with disabilities,
- institutions for adults with disabilities,
- institutions for elderly,
- psychiatric care institutions.

The objective of a representative sample of 15 000 persons has been met.
The structure of the questionnaire

The questionnaire was administered by interviews of 35 to 40 minutes long.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Number of items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impairments and their causes</td>
<td>8</td>
</tr>
<tr>
<td>Disabilities, their causes, and their duration</td>
<td>104</td>
</tr>
<tr>
<td>Social and familial environment</td>
<td>47</td>
</tr>
<tr>
<td>Family relationships</td>
<td>8</td>
</tr>
<tr>
<td>Access to housing and assistive devices</td>
<td>98</td>
</tr>
<tr>
<td>Housing conditions</td>
<td>30</td>
</tr>
<tr>
<td>Difficulties encountered in transportation</td>
<td>34</td>
</tr>
<tr>
<td>Transportation the day before the interview</td>
<td>9</td>
</tr>
<tr>
<td>School and level of education</td>
<td>27</td>
</tr>
<tr>
<td>Employment</td>
<td>77</td>
</tr>
<tr>
<td>Financial resources (salaries, allowances, insurance) and legal protection system</td>
<td>94</td>
</tr>
<tr>
<td>Administrative disability rate level</td>
<td>7</td>
</tr>
<tr>
<td>Leisure…</td>
<td>65</td>
</tr>
<tr>
<td>Socio-demographic characteristics</td>
<td>36</td>
</tr>
</tbody>
</table>

The questionnaire is the same as the household questionnaire except that it does not include questions related to the help provided by caregivers, the burden for caregivers, the description of the house and its adaptation due to health conditions.

Many questions not directly related to health conditions are worded in the same terms as they are in other INSEE surveys, in order to enable comparisons with the whole of the French population. It is the case for questions regarding leisure, social conditions, most of the questions related to employment and education etc.

Impairment data processing

The questionnaires were self-reported, except for people who were completely unable to answer or those who asked for some help. These three cases are evenly represented in the institution survey.

The self-reports of the impairments went through two correction procedures:
1- During the administration of the questionnaire, the interviewer had two opportunities of adding « new » impairments: a first time after having asked a question related to the cause of each disability, when people remembered an impairment they had forgotten to mention before. A second time, after the interview, the interviewer could add an obvious impairment that had not been mentioned by the person (neglected or denied). These two opportunities added 6 000 impairments to the 27 700 spontaneously self-reported.

2- A medical team checked the whole description of disabilities for each individual and eventually inferred « new » impairments from those disabilities. This procedure increased significantly the number of impairments, from 33 700 to 48 800. Added impairments were mainly related to vision, hearing and urinary problems.

Some main results
When the survey was conducted 664 253 persons were living in medico-social institutions, that is approximately 1.2% of the French population; among whom 71.2% were living in institutions for elderly and 98% declared having at least one impairment.

There is a majority of women, due to the weight of the elderly in the total population. (see table1).

Table 1: Persons living in medico-social institutions

<table>
<thead>
<tr>
<th>Type of Institutions (%)</th>
<th>Children and youth with disabilities 7.0%</th>
<th>Adults with disabilities 12.0%</th>
<th>Elderly 71.2%</th>
<th>Psychiatric institutions 9.8%</th>
<th>Total 100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numbers</td>
<td>Males 29 397 Females 16 769 Total 46 167</td>
<td>Males 46 926 Females 33 032 Total 79 957</td>
<td>Males 124 337 Females 348 956 Total 473 293</td>
<td>Males 36 714 Females 28 121 Total 64 835</td>
<td>Males 237 374 Females 426 879 Total 664 253</td>
</tr>
<tr>
<td>Rate (%)</td>
<td>Males 63.7% Females 36.3% Total 64.3%</td>
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Source: INSEE Premiere, n° 669, août 1999
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</tr>
</thead>
<tbody>
<tr>
<td>« living in a couple » %</td>
<td>Present couple</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Boy friend or girl friend</td>
<td>s.o.</td>
<td>5.6</td>
<td>7.4</td>
<td>15.4</td>
</tr>
<tr>
<td></td>
<td>Previously in couple</td>
<td>s.o.</td>
<td>22.8</td>
<td>1.8</td>
<td>8.1</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>s.o.</td>
<td>4.1</td>
<td>68.7</td>
<td>32.7</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>s.o.</td>
<td>67.5</td>
<td>22.0</td>
<td>43.8</td>
</tr>
</tbody>
</table>

The fact that the majority of the persons live alone in the institutions does not mean that they do not have family relationships.

The frequency of family relationships depends on the age of the persons. For obvious reasons, the group of the elderly presents the highest frequency of isolated individuals: 30% of them do not have regular contacts with their close family (2/3 of them having no longer a close family); 17% of the adults and 4% of the children do not have contacts with their families.
Graph N°1. Male / female distribution in French HID institutions

Source : INSEE Première, n° 669, août 1999

The study of the social status shows the overrepresentation of workers in the institutions. This is true even when there is no link between the social status, the impairment and living in an institution (for example, children) (see Graph.2).
The level of severity of disability is correlated to the impairments, age and type of institution.

The link between impairments and the nature and degree of severity of disabilities is strong but a little bit complex. Some types of impairments (such as locomotor impairments, for
example) seem to induce more disabilities than others (such as hearing impairments for example). Furthermore, the more impairments people declare, the higher their disability level (whatever synthetic indicator is used). Nevertheless, it also depends on the nature of associated impairments: the loss of intellectual capacity strongly worsen any other disability. This shows that the level of disabilities observed in French institutions is related to a number of factors.

Graph N°3. Level of disability in the different types of HID institutions

[Diagram showing the level of disability in different types of HID institutions]
If we consider the Katz Index, it clearly shows that the rate of persons who are independent for the six activities of daily living decreases when the age increases. The level of total independence is always higher for males than females (see Graph.4).

**Graph N°4. Rate of independent persons (Katz Index) according to their age**

These few results of the Institution Survey -interesting by themselves- get even more interesting when compared to those of the Household Survey; although the comparison has to take into account that the persons investigated in the Household Survey include a much more significant rate of persons with a low level of disabilities.

Once the data of the second Institution Survey are available, it will then be possible to examine the disability entry and exit flows.