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*Pascal Roussel:
The French survey "Handicaps, Incapacités,
Dépendance" (HID) in institutional settings*

The French survey *Handicaps, Incapacités, Dépendance*¹ (HID) in institutional settings
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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;

¹ The title of this survey may be translated as « Handicaps, disabilities and dependancy »

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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 were 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.

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

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

Type of Institutions (%)		Children and youth with disabilities 7.0%	Adults with disabilities 12.0%	Elderly 71.2%	Psychiatric institutions 9.8%	Total 100%
Numbers	Males	29 397	46 926	124 337	36 714	237 374
	Females	16 769	33 032	348 956	28 121	426 879
	Total	46 167	79 957	473 293	64 835	664 253
Rate (%)	Males	63.7%	58.7%	26.3%	56.6%	35.7%
	Females	36.3%	41.3%	73.7%	43.4%	64.3%

Source : INSEE Première, n° 669, août 1999

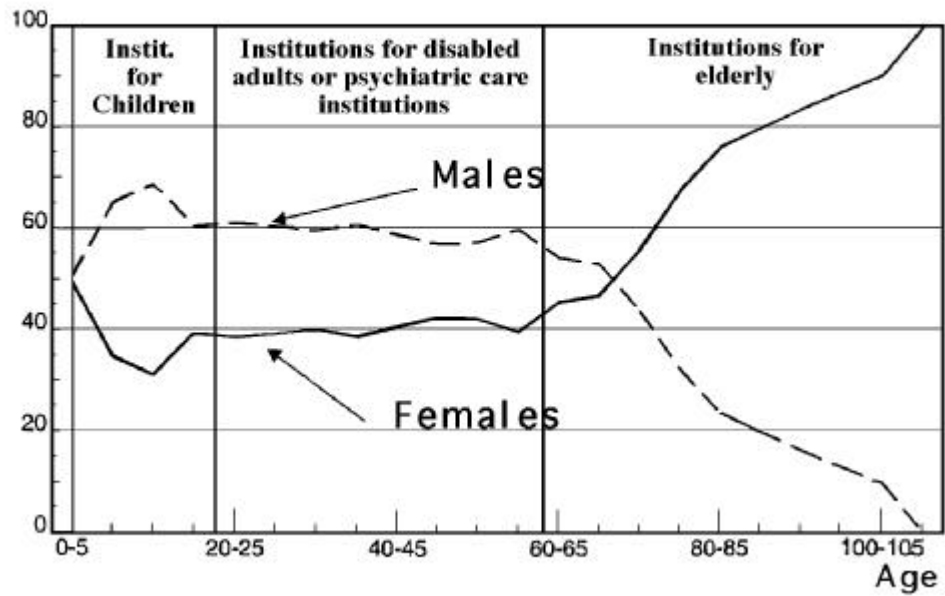
Table 2: Marital status of persons living in institutional settings

Type of Institutions (%)		Children and youth with disabilities 7.0%	Adults with disabilities 12.0%	Elderly 71.2%	Psychiatric institutions 9.8%	Total 100%
« living in a couple » %	Present couple	s.o.	5.6	7.4	15.4	8.0
	Boy friend or girl friend	s.o.	22.8	1.8	8.1	5.2
	Previously in couple	s.o.	4.1	68.7	32.7	56.8
	Never	s.o.	67.5	22.0	43.8	30.1

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.

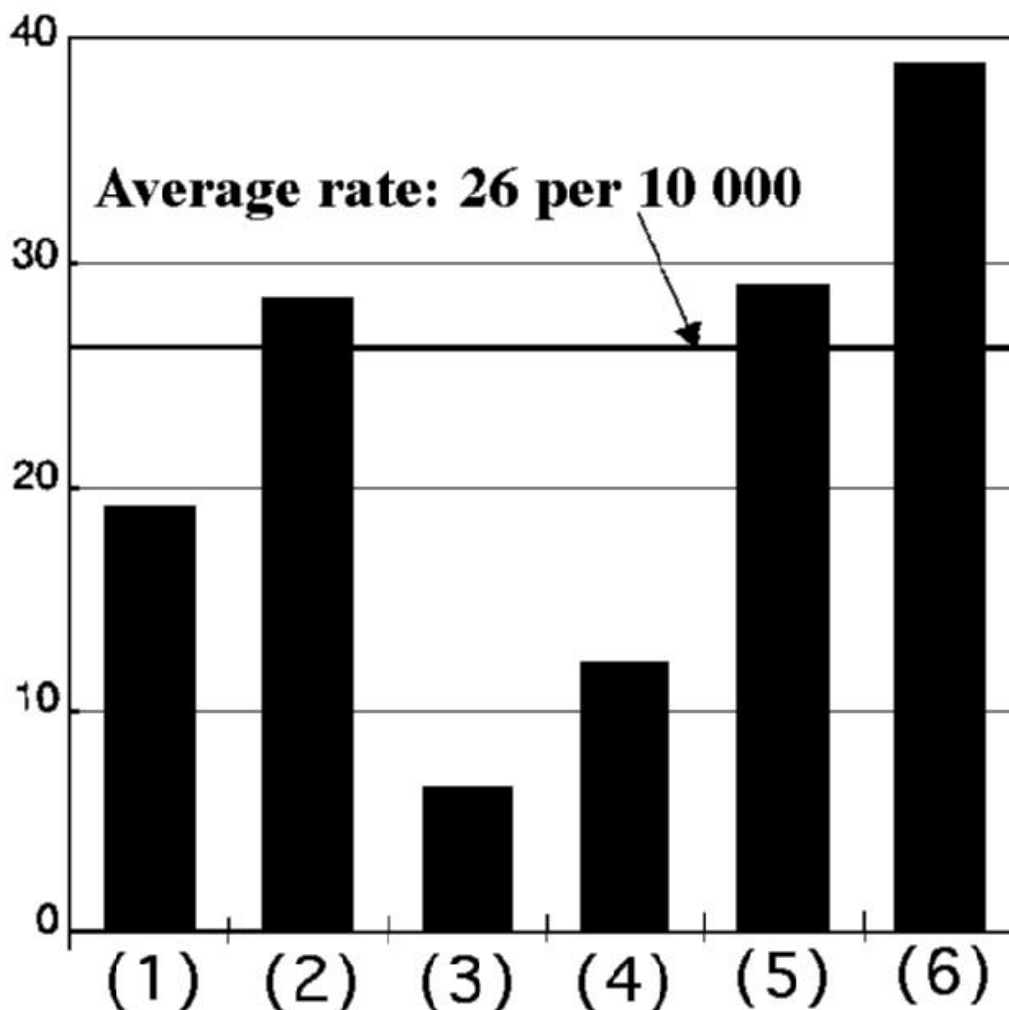
Graph N°1. Male / female distribution in French HID institutions



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).

Graph N°2. Professions and social categories in HID institutions



- (1) Farmers
- (2) Independents
- (3) Superior white collars
- (4) Middle class white collars
- (5) Employees
- (6) Workers

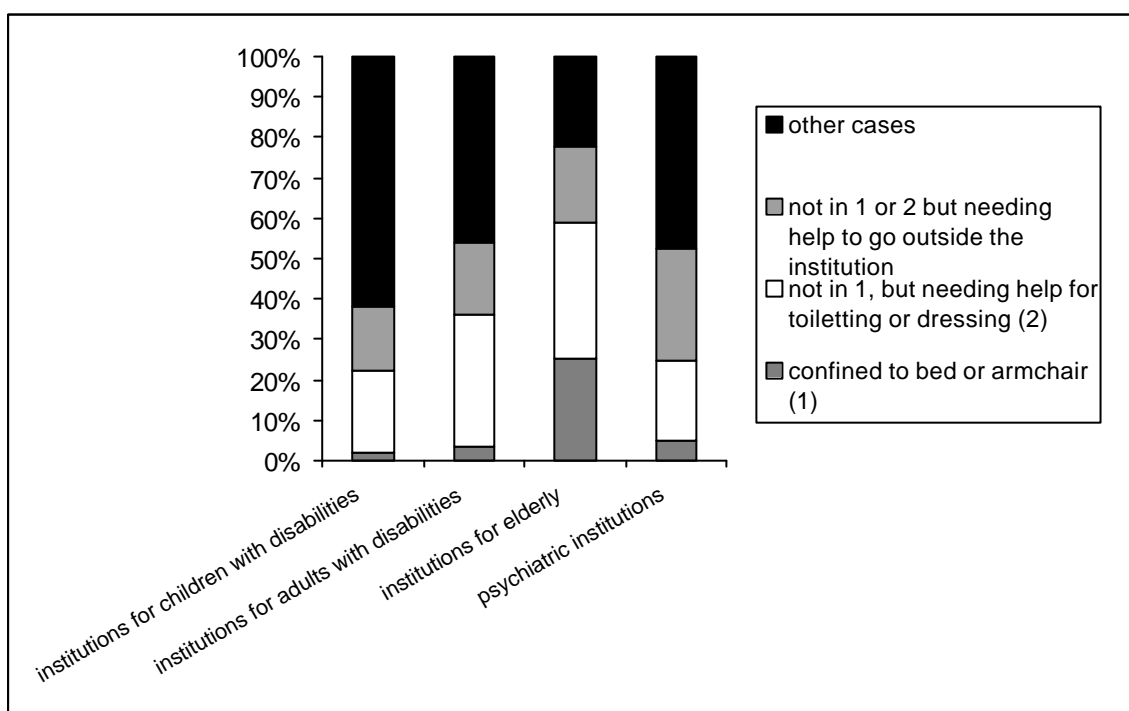
Source : INSEE Première, n° 669, august 1999

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

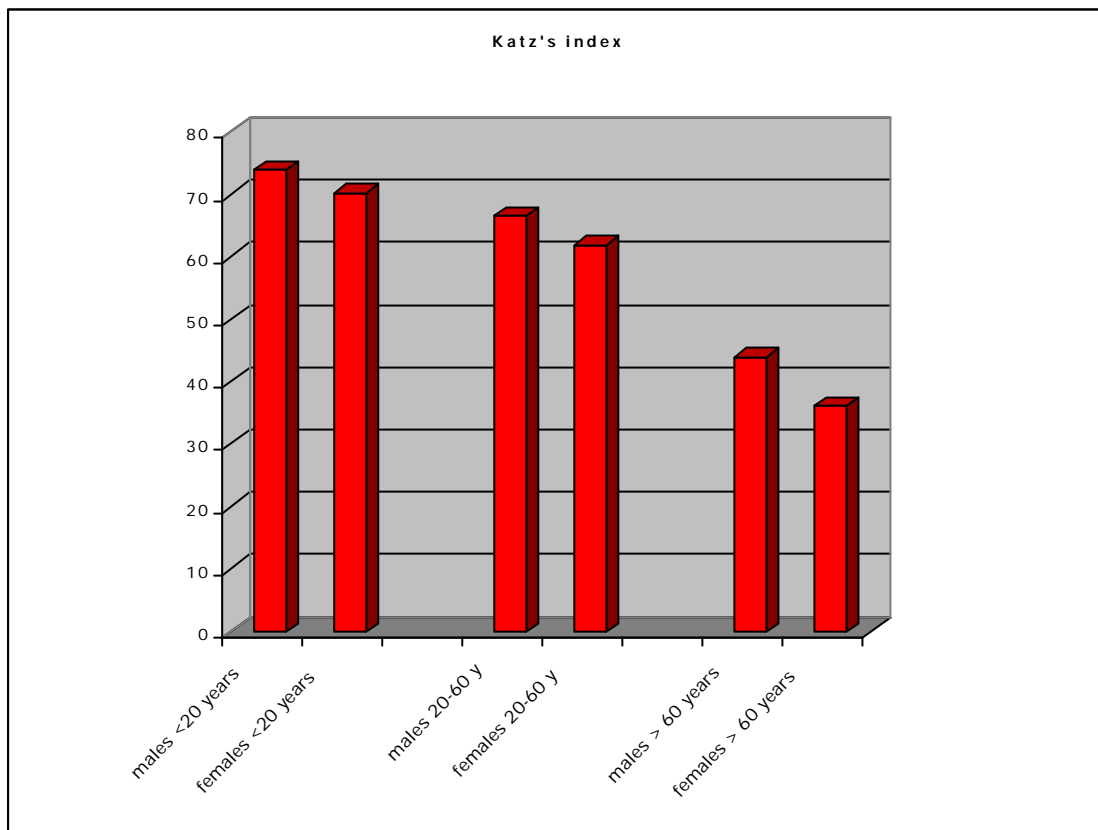
example) seem to induce more disabilities than others (such as hearing impairments for example). Furthermore, the more impairments people declare, the higher their disability level (whatever synthetic indicator is used). Nevertheless, it also depends on the nature of associated impairments: the loss 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



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.