

THE FRENCH POPULATION SURVEY OF HANDICAPS, DISABILITIES AND DEPENDANCE

METHOD

FIRST RESULTS IN PSYCHIATRIC INSTITUTIONS

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WHY A POPULATION SURVEY OF HANDICAPS IN FRANCE ?

Existing information is related to services, to institutions, or to limited geographical areas.

These various sources of information are difficult to compare with each other.

International experience exists in the field of handicap surveys (U.S.A., Canada, Australia, U.K., etc.)

Requested by policy makers and by associations of people with disabilities.

ORGANIZED BY THE INSEE

(Institut National de la Statistique et des Etudes Economiques)
National Institute for Statistics and Economic Studies

WITH THE HELP OF RESEARCH INSTITUTES

INSERM (Medical Research)

CTNERHI (Research about handicaps)

INED (Demographic studies)

CREDES (Economic studies about health)

MIRE and DREES (Ministry of Health research agencies)

WHO Collaborating Center in Mental Health

PROJECT GROUP : FOUR YEARS PREPARATION

PURPOSES OF THE SURVEY AND EXPECTED RESULTS

To study “ **Disabilities** ” as defined by the W.H.O. in the International Classification of Impairments, Disabilities and Handicaps ; to look for the **causes** of these disabilities in terms of impairments ; to look for the **consequences** of these disabilities in terms of social disadvantages, and of consequences for the “ main helper ”.

To estimate the number of handicapped or dependent persons, by sex and age, over the **entire population** (at home or in an institution *with two extensions : one for prisons, one for the homeless*) : to estimate a “ potential need for help ”

To study not only **prevalences** but also **incidences** : to estimate the in- and the out-flows, as a necessary basis for prediction for future years.

To provide a basis for comparison between the help received and the need for help : to provide a detailed description of the social, human, and material **environment**.

To enable measuring according to the schedules most frequently used in France, (A.D.L., I.A.D.L., COLVEZ, AGGIR, etc.) in order to ensure comparability with existing statistics.

To estimate the severity of disabilities and handicaps, in order to provide information for policy decisions (how many people would be involved in a new policy)

To estimate the number of people who suffer from a major impairment (how many people are blind, how many require technical assistance, etc.)

To provide information about the origin of impairments : for instance : about paralysis of the lower limbs, to estimate how many were caused by polyomyelitis, traffic accidents, etc, in order to compare the priorities and cost of public health actions.

To provide information about the frequency of the most important disabilities in ordinary life (mobility, self care, communication, managing money, managing medications, etc.) in order to provide information about the need for help, and about the required qualifications of the helpers.

To estimate disadvantages in education, employment, transportation, etc., in order to help estimate the needs in special education, sheltered work, urban design, etc.

To estimate consequences for family helpers, since help to helpers is a major tool in order to help people stay at home.

To provide results or estimates at a local level (“ départements ”) for local policy makers.

IMPORTANT DATES

1998 : **Institutions survey**

14 587 people in the sample

1999 : **Home survey**

First step at the same time as the national census (march) : 300 000 to 400 000 people have answered a small questionnaire

Second step : a sample of 16 924 have answered a large questionnaire

2000 : **The same people who were surveyed in 1998**

2001 : **The same people who were surveyed in 1999
+ Prison survey**

Later : **A cohort study of mortality rates is being considered**

ESTIMATED COST

(1US\$ ≈ 6FF)

1 - Preliminary studies (1995-1997)

FF	4 280 450
US\$	713 410

2 - Institutions survey (1997-1999)

FF	12 860 000
US\$	2 143 333

3 - Home survey (1998- 2000)

FF	16 470 000
US\$	2 745 000

4 - Second survey of the 1998 people (1999-2001)

FF	10 930 000
US\$	1 821 666

5 - Second survey of the 1999 people (2000-2002)

FF	12 250 000
US\$	2 041 666

TOTAL :FF	56 790 450
US\$	9 465 075

OUTLINE OF THE QUESTIONNAIRE

(Institutions)

A- Cause and origin of the disabilities

B- Description of the disabilities

- Washing
- Dressing
- Feeding
- Elimination
- Mobility
- Transferring
- Moving around inside the building
- Moving around outside the building
- Purchases
- Distant communication
- Coherence
- Orientation
- Sight, Hearing, Speech
- Suppleness and manual dexterity

C- Social and family environment

- Couple and family
- Father, mother, and other relatives
- Other family and friends

D- Technical assistance, organization of the building

- Access to the building
- Changes to the building for access
- Protheses and appliances
- Assistance with personal care and protection
- Assistance with personal mobility
- Assistance with communication, information and signs
- Assistance with manual operations

Assistance with treatments
Other assistance

E- Dwelling

Before entering the institution
Description of the living environment in the institution
Expectations for the future

F- Moving around

Outside the institution
Driving
Other problems (public transportation, etc.)

G- Schooling and diplomas

H- Employment

Present situation if employed
Present situation if not employed
Past situation

I- Income

Amount and origin
Legal status and administrative implications

J- Disadvantages

Holidays
Movies, theatre, concert, etc.
Associations, clubs, etc.
Sports,
Quality of life (sleep, health, unmet needs)

PARTICIPATION RESULTS

2075 institutions were drawn ; 155 refused (7.5%)

Institutions for children with disabilities	Institutions for adults with disabilities	Institutions for senior citizens	Psychiatric Institutions
6.5%	4.5%	4.5%	17%

PSYCHIATRIC INSTITUTIONS INCLUDED :

All institutions where patients will stay overnight

Psychiatric public hospitals

Psychiatric wards in general hospitals

Psychiatric private hospitals

Estimated population at the time of the survey : 68 922

AGE		
0 – 19	3 200	5%
20 – 39	23 300	34%
40 – 59	28 300	41%
60 – 79	11 500	17%
Over 80	2 000	3%
Total	68 900	100%

MARITAL STATUS

	MEN		WOMEN	
	Observed	Expected / age	Observed	Expected / age
Bachelors	72%	30%	50%	20%
Married	13%	61%	23%	58%
Widowers	3%	2%	15%	14%
Divorced	12%	6%	13%	8%

WHAT YEAR DID THE PERSON ENTER THE INSTITUTION ?

1998	61.3%	42 200
1997	8.4%	5 800
1993 – 1996	11.5%	8 000
1988 – 1992	4.8%	3 300
Before 1988	14.0%	9 700

Note : the survey took place in October – December 1998

THE LONGER THE STAY, THE MORE SERIOUS THE PROBLEMS

	Three months or less	Over five years
Bachelors	42%	87%
Can read, write, and count	90%	40%
Have a job	29%	3%
Receive a state allowance	31%	86%

NOT ALLOWED TO GO OUTSIDE			
Rate in the age group			
	Institutions for adults with disabilities	Institutions for senior citizens	Psychiatric institutions
20 – 39 years	13.0	0.0	21
40 – 59 years	10.5	9.7	23
60 – 79 years	10.9	13.9	32
All	12.3	17.8	25

NOT ALLOWED TO GO OUTSIDE			
How many persons			
	Institutions for adults with disabilities	Institutions for senior citizens	Psychiatric institutions
20 – 39 years	6 390	0	4 600
40 – 59 years	3 020	630	6 100
60 – 79 years	380	15 600	3 300
All ages	10000	73600	17000

PSYCHIATRIC INSTITUTIONS

Cannot go outside alone because of psychological or emotional problems

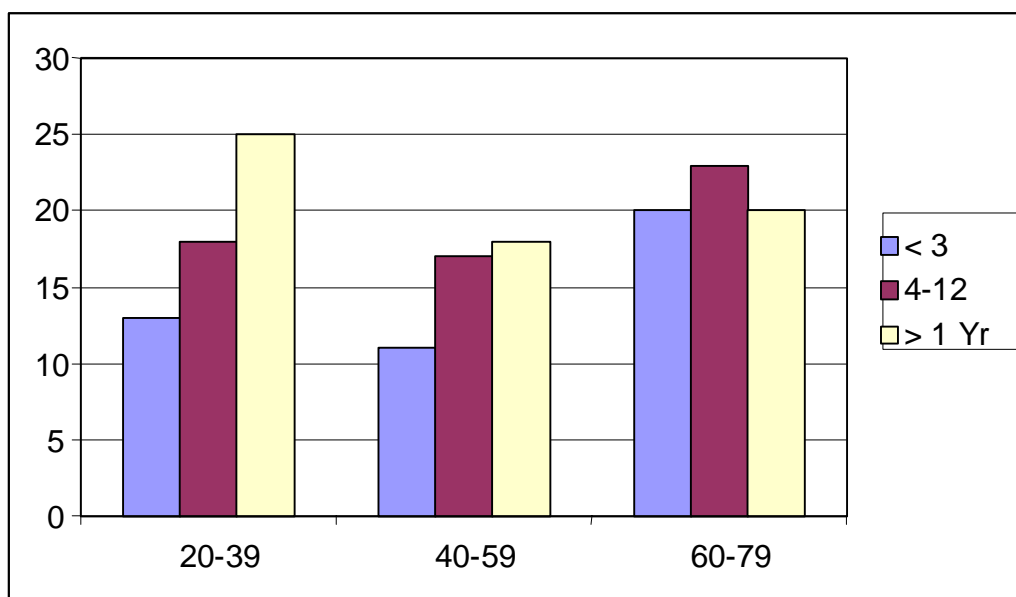
Rate in the age – and length of stay - group

	20 – 39	40 – 59	60 – 79	20- 79
<=3 months	13	11	20	14
4-12 months	18	17	23	19
>1 year	25	18	20	21
All	19	15	21	17

Cannot go outside alone because of psychological or emotional problems

How many people in the age – and length of stay - group

	20 – 39	40 – 59	60 – 79	20- 79
<=3 months	1300	1300	1000	3600
4-12 months	900	700	550	2150
>1 year	2000	2200	850	5050
All	4200	4200	2400	10800



**PROPORTION OF PEOPLE WHO SAY
THAT THEIR DWELLING IS VERY
SATISFYING *OR* SATISFYING**

Institutions for adults with disabilities	Institutions for senior citizens	Psychiatric institutions
78%	81%	62%

PEOPLE WHO WERE IN A PSYCHIATRIC INSTITUTION BEFORE ENTERING ...

...an institution for senior citizens :

15 500 out of 419 400

...an institution for adults with disabilities :

5 900 out of 86 000

BEFORE ENTERING THIS PSYCHIATRIC INSTITUTION, THEY WERE...

...in an institution for senior citizens :

2 100 out of 68 900

...in an institution for adults with disabilities :

4 400 out of 68 900

PEOPLE WHO :

- **ARE IN A PSYCHIATRIC INSTITUTION,**
- **AND SHOULD ENTER AN INSTITUTION FOR ADULTS WITH DISABILITIES (COTOREP DECISION)**
- **AND ARE NOT ACCEPTED : “ NO PLACE AVAILABLE ”**

26% of the people with a COTOREP decision

Sheltered work (CAT, AP) :	30%
Rehabilitation structure :	15%
Sheltered dwelling (foyer, MAS)	29%

AS COMPARED TO PEOPLE WHO :

- **ARE ALREADY IN AN INSTITUTION FOR ADULTS WITH DISABILITIES**
- **AND SHOULD ENTER ANOTHER INSTITUTION FOR ADULTS WITH DISABILITIES (COTOREP DECISION)**
- **AND ARE NOT ACCEPTED : “ NO PLACE AVAILABLE ”**

1% of the people with a COTOREP decision