

French institutions will show an increase of 56.3% by 2020 mainly due to the aging of the population. In 2000, institutionalization represented 0.62% to 2.71% of the GDP (Gross Domestic Product) in OECD countries. Increases of up to 69.5% in the number of institutionalized individuals are expected by 2020 [4].

In 2001, according to the World Health Organization (WHO), visual impairment was responsible for 2,286,000 DALY (disability adjusted life years) in the high income countries. [5]. The prevalence of blindness and low vision (LV) for people living in institutions has never been estimated at a national level as far as we are aware. The use of registers to estimate the prevalence of blindness is controversial since a high proportion of blind individuals are not registered [6-9]. Studies were conducted in institutions [10-12], but never from a representative nationwide sample. None of them documented the level of disability linked to visual impairment. Visual impairment prevalence rates varied from 7.4% to 23.0%, this range being mainly explained by different definitions of visual impairment. Since blindness and/or LV could be one of the impairments leading to institutionalization in elderly individuals, the comparison of prevalence in the community and in institutions is a key issue.

The social and economic consequences of blindness (disability, dependency and need for assistance) have never been evaluated, in France, at a national level with a representative sample of individuals living in institutions. This information is important for several reasons: (1) institutions have to provide the right level of assistance for each different type of impairment, blindness being one of them; (2) a handicap needs to be indemnified (directly or indirectly) and therefore its economic burden have to be estimated to determine the level of social allowances; (3) macro-economic consequences of blindness need to be estimated to determine how much should be budgeted and invested to care for this handicap at a national level in the long term.

The present survey had three aims: (1) to estimate the prevalence of self-reported blindness and LV in French individuals living in institutions, on a national basis; (2) to study the consequences of self-reported blindness and LV, focusing specifically on disabilities (restricted ability, or inability to perform the activities of daily living) and handicaps (restricted ability, or inability to fulfill desired social roles); (3) to collect information on the economic consequences of income level and social allowances.

## Methods

This survey was conducted at the request of the French State which also provided the finance. The data were gathered by INSEE (Institut National de la Statistique et des

Etudes Economiques) which is the State agency responsible for executing regular national census surveys. This survey complied with all existing national regulations, including personal data privacy and access. The database was subsequently made available to researchers for secondary analyses.

The methodology of this survey has already been described elsewhere[13]. Cluster sampling was used.

2,075 institutions were randomly selected from French Health Ministry files (day care centers were excluded). French institutions are classified into four types according to the nature of the residents: children with handicaps, adults with handicaps, the elderly and psychiatric patients. The sample was stratified by 4 main categories of institutions (Table 1). The probability of an institution being selected was inversely proportional to the number of institutions in the category, and was proportional to the number of beds. Fifty-seven had to be replaced: 37 had no residents, 18 no longer existed, and the survey was not technically possible in seven centers. One hundred and fifty-five (7.5%) of the institutions refused to participate. Refusal rates varied by type of institution: 6.5% in centers for handicapped children, 4.5% in centers for handicapped adults, 4.5% in elderly care homes and 17.0% in psychiatric centers. The most frequent reasons for refusal to participate were lack of time (22.7%), the non-compulsory (this survey was disconnected from the national census) nature of this INSEE survey (10.7%), lack of staff to help the interviewer (7.3%), disturbance of the residents (5.3%), institution being restructured (3.3%), violation of privacy (2.7%), too many surveys (2.7%), and beliefs that the questionnaire was not adapted to the residents (2.7%).

Of these institutions, 15,403 individuals were taken at random by the interviewers from the resident lists (eight per institution) and 14,611 interviews (94.9%) were performed. The analysis was performed on the 14,603 patients with documentation of handicap (eight interviews were stopped before the handicap was documented).

The questionnaire is available from the INSEE upon request by researchers.

No exclusion criteria were specified (e.g. age, cognitive functioning, etc..) and proxy responded when required by the health status of the interviewed. The presence of handicap was identified by the following initial "yes/no" question: "In everyday life, are you faced with either physical, sensorial, intellectual or mental difficulties (resulting from an accident, a chronic disease, a problem at birth, a disability, aging ...) ?" Independent of the answer, the