



THE HEALTH OF DEAF AND HARD OF HEARING

Data from the survey "Health Barometer for Deaf and Hard of Hearing", 2011/2012

This document presents some of the results of the first Inpes survey on the behaviour and health of people affected by hearing disorders. The subjects covered are mental health, the employment situation, use of and access to care, expectations regarding health information, use of psychoactive substances and sexuality.

BACKGROUND

The Health Barometer for Deaf and Hard of Hearing (BSSM) is a survey conducted by the National Institute for Health Promotion and Health Education (Inpes) in partnership with the Caisse Nationale de Solidarité pour l'Autonomie [French national funding agency for the elderly and handicapped] (CNSA). It is an offshoot of an Inpes survey of the general population, the Health Barometer 2010, which examines views and behaviour concerning risk taking and the health of the population resident in mainland France.

The BSSM is interested in people affected by deafness but also those with hearing disorders such as tinnitus (whistling or buzzing) or hyperacusis (am-

plification of hearing, sometimes to the point of becoming painful).

This study, presenting results on several health subjects in these populations, is the first of its kind. It contains questions on mental health, occupational health, access to information and care, use of tobacco, alcohol and cannabis, or sexuality, among others. The survey was carried out thanks to the exceptional dedication of the institutions, professionals and associations concerned. It was prompted by a lack of data on the health of these populations who are often hard to reach with surveys, that are generally conducted by telephone.

SURVEY METHOD

REFERENCE POPULATION

The BSSM survey, carried out in 2011/2012, questioned 2994 people aged 15 years and over living with decreased hearing acuity and/or other hearing disorders. The aim was to obtain a range of respondents in terms of age, level of deafness or level of trouble caused by tinnitus and/or hyperacusis, the time the deafness or other hearing disorders started and whether or not they used sign language. The sample is essentially made up of people who had become deaf before the age of 60 years. Among those surveyed, 900 were users of French sign language (FSL) and 900 said they experienced great difficulties because of tinnitus and/or hyperacusis. These populations are important as regards earlier surveys carried out among deaf and hard of hearing populations abroad and in France.

People with hearing disorders in France is estimated by the Handicap Santé Ménages [Disability Household Health] (HSM) survey to be about seven million. Among these, the number of deaf people using FSL is not accurately known, but is probably about

100,000. In the Handicap-Incapacité-Dépendance [Disability-Incapacity-Dependence] (HID) and HSM surveys, the figures are said to be around 80,000 and 56,000 people respectively, but these data are certainly an underestimate, since no specific method had been selected to study them. From these same surveys, it can be estimated that the number of people living with tinnitus is about two million.

DATA COLLECTION METHOD

The data were collected using an online questionnaire. To motivate the people concerned to take part in the study, a broad-based advertising campaign was run *via* various networks (associations, institutions, health professionals) and means of communication (emails, banner adverts on websites, prospectuses and posters, videos, articles, etc.). So as not to exclude respondents with no Internet access, an additional survey tool was used at home, with the assistance of the associations, to help these populations answer the online survey. The sample assembled in this way cannot, however, make any claim to being representative of people with hearing disorders.

The questionnaire was adapted from the Health Barometer 2010 and reduced to ensure that the survey took an average of no more than 30 minutes to complete. The basic rule was to keep the maximum number of health subjects despite reducing the number of questions. An Internet survey was conducted among professionals and people concerned, to collect information about the subjects they considered priorities. The results of the sur-

vey served as the basis for this choice. In addition, subjects considered to be important for the people questioned were added or expanded. These were occupational health, parenthood and questions directly linked to deafness or other hearing disorders. The questionnaire was adapted into sign language so that, for each written question, there was a video in FSL on the same web page.

MENTAL HEALTH

Living with impaired hearing does not always have the same consequences, which depend on the age at the onset of deafness, the level of hearing acuity, the means of communication (French, FSL, human and technical aids, etc.) or the presence of hearing disorders such as tinnitus or hyperacusis. However, whatever the situation as regards hearing, the perception of health, particularly mental health, seemed to have considerably worsened in the people questioned in the BSSM.

By comparison with the general population questioned in the Health Barometer 2010 [table 1]:

- twice as many respondents in the BSSM report poor or indifferent health;
- almost three times more are affected by psychological distress;
- respondents to the BSSM report five times more suicidal thoughts over the last 12 months and nearly three times more report attempted suicide during their lives.

TABLE 1 Comparison of quality of life and mental health indicators in the BSSM 2011/2012 and the Health Barometer 2010 (adjusted data) (%)

	BSSM (in non-users of FSL)	BSSM (in users of FSL)	Health Barometer 2010 (general population)
Health perceived as indifferent or poor (15-75 years)	24.3%	14.1%	9.8%
Psychological distress in the last 4 weeks*	46.8%	42.7%	16.7%
Suicidal thoughts in the last 12 months	21.4%	18.4%	3.9%

* Psychological distress is defined by the MHI-5 (Mental Health Index). This score is based on the replies to five questions: "In the last four weeks, were there times when you felt very nervous/so dejected that nothing could lift your mood again/calm and relaxed/sad and downcast/happy?" with the possible replies "all the time/often/sometimes/rarely/never". Individuals with a score strictly below 56 are considered to be in psychological distress.

Psychological distress is important whatever the sociodemographic profile or the situation as regards hearing. However, it is more often diagnosed when people mention:

- fatigue linked to everyday communication;
- hearing disorders (tinnitus and/or hyperacusis) that are very troublesome in everyday life;
- other physical disabilities (linked to motor, cardiorespiratory or visual disorders and/or pain);

- psychological violence experienced in the last 12 months and, for men, sexual violence during life.

It should be noted that physical or psychological aggression reported during the year and sexual violence experienced during life are two to three times more common than in the general population.

HEALTH AND WORK

SUFFERING AT WORK

The symptoms of lack of discomfort are also strongly linked to work situations:

- 34.0% of the working population is in a situation of psychological distress attributed to work (vs 5.4% of the general population);
- 10.3% of workers considered committing suicide in the last 12 months because of their work situation (vs 1.4% of the general population);
- 3.5% of the working population report one or more suicide attempts during life for work reasons (vs 0.6% of the general population).

Psychological distress and suicidal thoughts for work reasons are more common in people who report great hearing difficulties and in those who have difficulties understanding their colleagues in written or oral communication.

People who report "physical fatigue" at work more often have very troublesome tinnitus and/or hyperacusis. They are also the ones who report more "nervous fatigue" at work.

Discomfort at work is associated with particular situations. It is more common when people encounter problems communicating with work colleagues. One third (33.9%) of working people reported difficulties making themselves understood

by colleagues (in writing or orally) and more than two thirds (69.9%) had difficulties understanding colleagues when they spoke or wrote to them. Suffering at work is also associated with less decision-making freedom, a lack of resources (poor support from colleagues, resources insufficient to do quality work) or also with situations involving productivity demands or tension with the public. These poor working conditions are reported more often than in the general population (Health Barometer 2010). Paradoxically, many are troubled by noise at their place of work, even though that has less effect on people with very reduced hearing acuity.

This work-related suffering is not inevitable, however, as 18% report well-being linked to working life. These are most often FSL users but also people working in more favourable conditions (more support from colleagues, resources allowing them to do quality work, fewer situations of tension with the public).

SITUATION REGARDING EMPLOYMENT

As regards the data from the Health Barometer 2010, the proportion of those aged 15-64 years in the BSSM in work is markedly less than that in the general population, and the unemployment level is higher. More than half (53.6%) of unemployed peo-

ple need human assistance in their attempts to find work.

Among employed people, one in five (21.2%) reported working part time (27.2% of women vs 9.1% of men). In one quarter of situations, the part-time working was for health reasons or due to disability. As in the general population, the amount of part-time working the person was subjected to (imposed by the employer) was larger for men than for women.

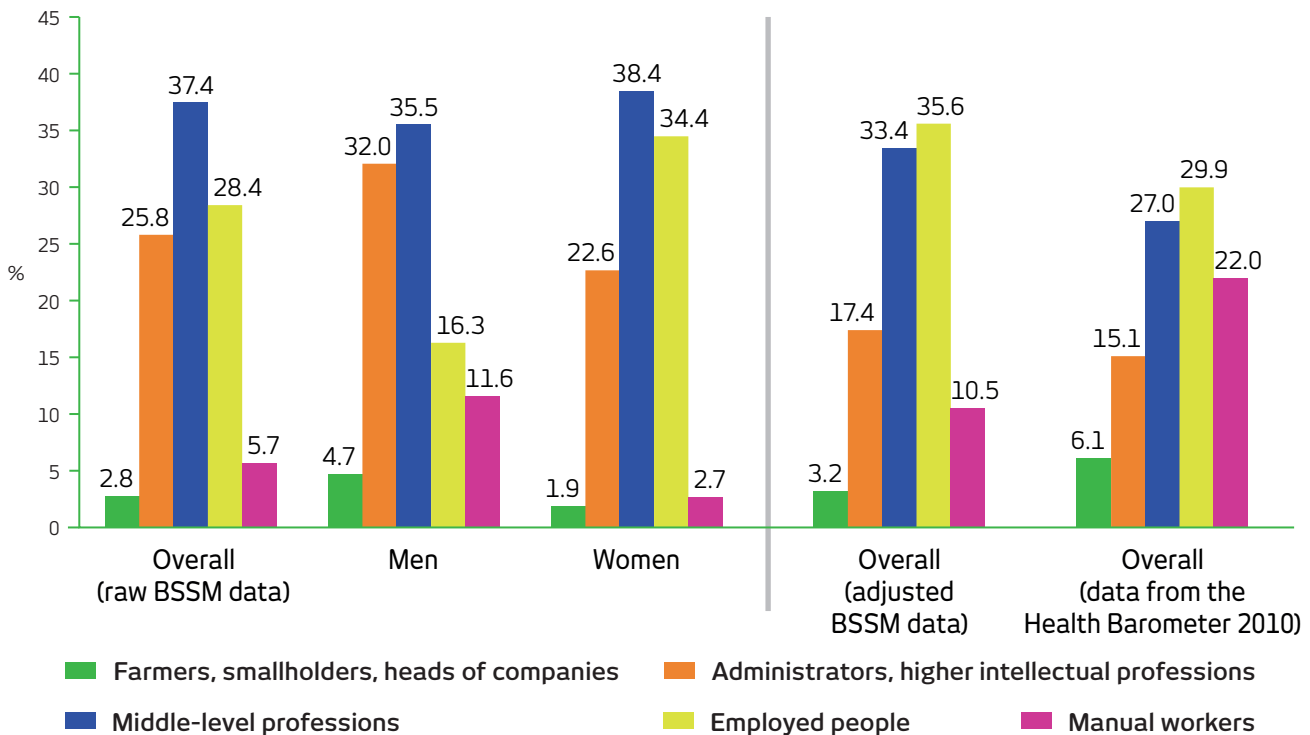
By comparison with the population in the Health Barometer 2010, that of the BSSM is characterised by a significantly larger proportion of middle-level professions and salaried staff, and by a smaller proportion of manual workers and freelance workers [figure 1].

RECOGNITION OF DISABILITY

More than six working people in ten (63.1%) have the recognised status of disabled workers (RSDW); this figure is 93.6% among people who cannot hear at all or are FSL users. Almost one employed person in ten (8.9%) enjoys flexible working hours; this situation is closely linked to having the recognised status of disabled worker.

One quarter (24.9%) of working people said that they received personal aids to communicate in their work. If these aids are in proportion to the ability to hear, almost half (43.2%) of the people who say they cannot hear at all and two thirds of those who hear with great difficulty (65.2%) work without any aids. In addition, only 38.5% of people with RSDW receive aids to work.

FIGURE 1 Proportion of working people employed, by sex and socio-occupational category, in the BSSM 2011/2012 and the Health Barometer 2010 (%)



Sources: BSSM 2011/2012, Baromètre santé 2010, Inpes.

ACCESS TO AND USE OF HEALTH CARE

CONSULTATION OF HEALTH PROFESSIONALS

Over the last ten years or so, the availability of aids and use of care by deaf people has changed considerably, in particular through the recognition of sign language, the creation of adapted consultations and through the training of health professionals. However, communication with health professionals is still difficult for those who are deaf and may, particularly for those in unfavourable economic circumstances, impede access to care and the quality of care dispensed.

By comparison with the general population, BSSM people consult general practitioners, psychologists, psychiatrists and acupuncturists on a more frequent basis. This result should be seen in the context of a greater incidence of chronic diseases and situations of psychological stress. As regards contraceptive or gynaecological follow-up, women in the BSSM consulted a gynaecologist less frequently in the last 12 months. Finally, ENT consultations decrease regularly with increasing age and are more commonly made by people who say they are greatly troubled by tinnitus and/or hyperacusis (66.6% vs 45.4%).

In the last 12 months, 20.2% of those questioned had consulted a medical unit adapted to deaf and hard of hearing people. Proportionally more deaf FSL users use these services (24.6% vs 18.2%).

CANCER SCREENING

Questions were asked about the use made of three types of cancer screening. Among those aged 50-74 years, eight women out of ten had had a mammography in the last 2 years, a proportion which is identical to that in the general population. By contrast, fewer of the women in the BSSM had undergone a cervical smear in the last 3 years; this difference ceases to exist when examinations in the course of life are considered. Similarly, in men a smaller proportion of those aged 50-74 years had been screened for colorectal cancer in the last 2 years, but made more use of that screening in the course of their lives.

DIFFICULTIES ENCOUNTERED AS REGARDS USE OF CARE

Two types of persons experienced particular difficulties concerning the use of care in the last 12 months:

- people with chronic diseases and/or troublesome tinnitus and/or hyperacusis.

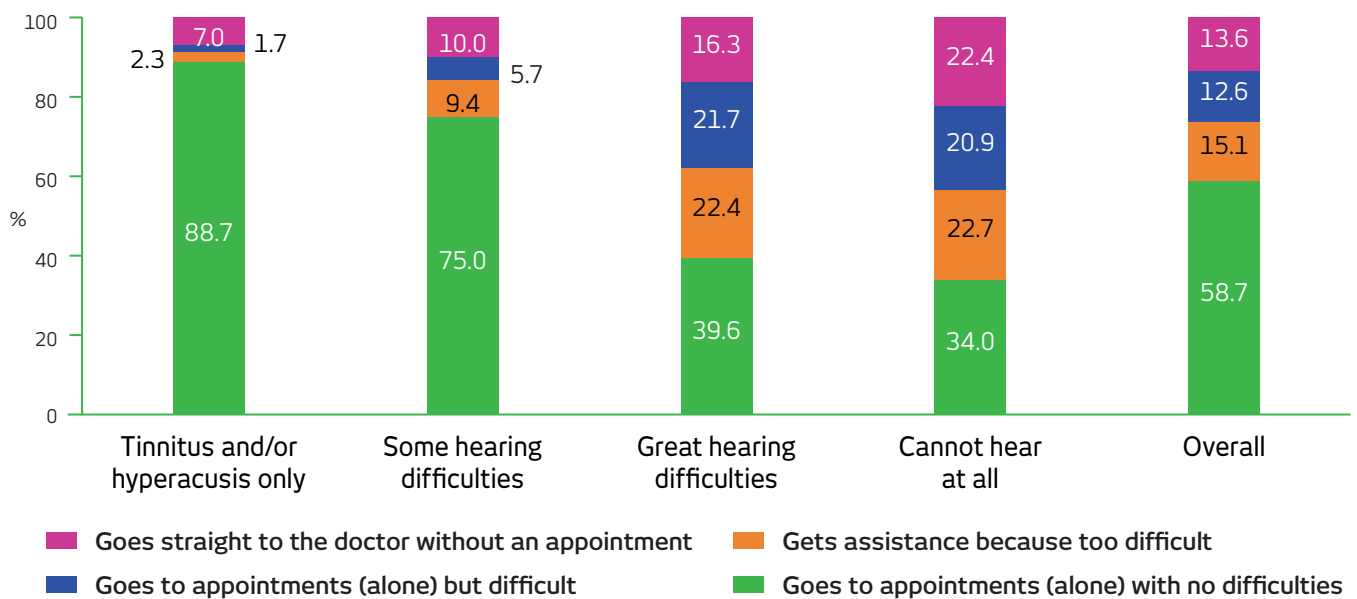
They are strongly represented among survey respondents who said they had to go without care for financial reasons. These populations probably can't fulfil their large needs for specialised consultations. A high level of care use may also be a sign of a lack of satisfactory provision, particularly for tinnitus and/or hyperacusis;

- FSL users and/or those with problems of oral expression.

They are more commonly found among those who said they never consulted a specialist during the year, or among those reporting difficulties getting an appointment with a general practitioner (41.3% of those who consulted are in this situation) [figure 2]. These difficulties delay visits in 30% of cases and, in 18.0% of cases, often prevent patients from consulting at all.

The BSSM also contained questions about means of communication with doctors and the difficulties that could arise at this level. Deaf people using FSL are also part of the minority (5.7%) who systematically use a third person to communicate with the GP. In this case, use is made, in six cases out of ten, of a relative, in one case in four of an interpreter, and in one case in ten of a writing specialist. The assistance of a third person proves to be embarrassing for half the people concerned, so much so that half of them often go without care.

FIGURE 2 Ability to attend an appointment with the general practitioner according to perceived hearing acuity (%)



Source: BSSM 2011/2012, Inpes.

INFORMATION ON HEALTH

Information on health, whether disseminated *via* the media or during exchanges with health professionals, is a particular challenge for the deaf and hard of hearing because of the difficulty in accessing the information. Audio information is out of the question for those with the most severe deafness, but so is video if there are no subtitles. The method of communication used by health professionals is not always adapted to the needs of patients, and the presence of an interpreter for those using FSL or of a coder for French Cued Speech (FCS)¹ is not always easy to

organise. In addition, for people who have been deaf since early childhood, written comprehension may be limited, for want of suitable training, and is not always made up for by, in particular, information in FSL.

However, the feeling of being informed within the audiences concerned by BSSM is on the whole similar to that observed in the general population (Health Barometer 2010). A question was in fact included to find out whether people felt well-informed about ten or so health subjects such as sexually transmissible diseases, cancer or Alzheimer's disease. On the other hand, in some situations, people less often feel well-informed. This is particularly the case for those expressing themselves orally,

1. The FCS code aids comprehension of French by means of coded hand-shapes near the face and can be used to supplement what is said. It is intended to avoid any confusion arising from lip-reading.

who have difficulties reading or for whom deafness started early.

Questions were then asked about fears concerning subjects such as accidents in everyday life, cancer or Alzheimer’s disease. It emerged that they are no greater than in the Health Barometer 2010. On the other hand, the rate of non-response to this question increases with reading difficulties, which undoubtedly reflects a lack of information about the subjects in question.

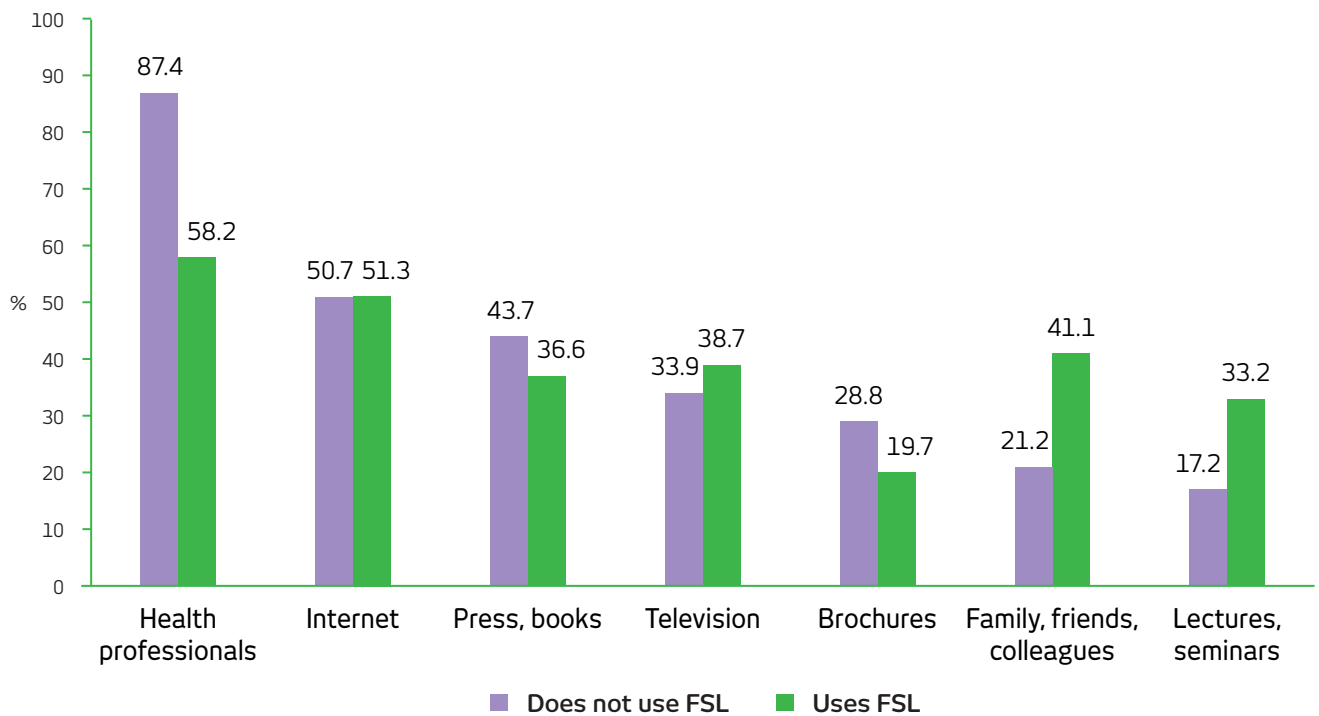
When asked about the preferred means of receiving health information or advice, those surveyed placed health professionals (79% of respondents) ahead of the Internet (51%) and writing (press, books: 42%) [figure 3]. For those who use FSL or those with limited access to reading, information from close friends and relatives and lectures in

sign language are more important, to the detriment of paper sources and professionals who do not use FSL.

Using the Internet to look for health information was the case for more than three quarters of those questioned, compared with one third of the sample in the Health Barometer 2010. Logically, this medium is particularly popular with the survey populations since it partly replaces the telephone, radio and television as a means of getting information and exchanging views.

When asked if people want health information, 36% replied in the affirmative. FSL users are interested in a large variety of subjects and particularly by serious diseases. Those who do not use FSL ask mainly for information about deafness and other hearing disorders.

FIGURE 3 Preferred sources of information, according to whether or not people use French sign language (%)



Source: BSSM 2011/2012, Inpes.

USE OF PSYCHOACTIVE SUBSTANCES

The levels of use of the three psychoactive substances the BSSM population was asked about, namely tobacco, alcohol and cannabis, differ from those of the general population (Health Barometer 2010).

Thus, a reduction in daily smoking (-11 points) and in binge drinking (consumption of at least 6 glasses on the same occasion) during the year (-7 points) or at least once a month (-7 points) is found.

On the other hand, no difference is found as regards alcohol consumption over the year, daily consumption or consumption leading to chronic risk or dependence.

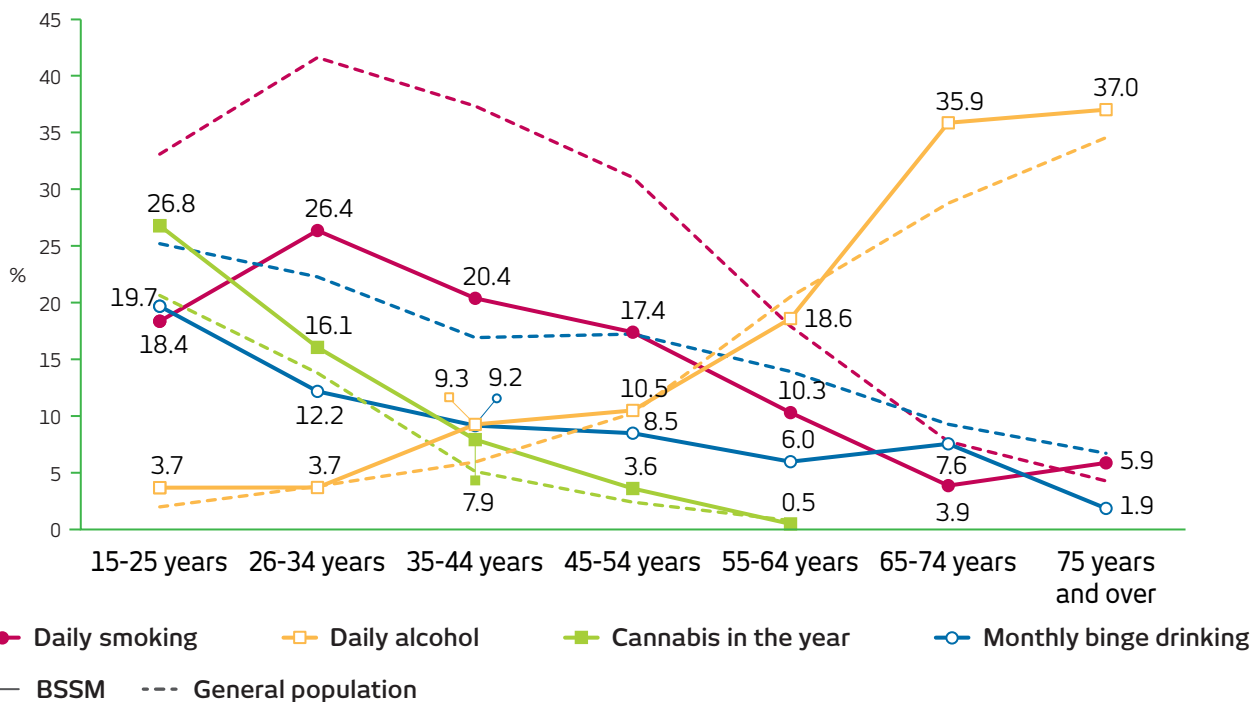
Finally, experimentation with cannabis proves to be

a little more common among people who replied to the BSSM (+6 points). However, recent and regular use are of the same order as those observed in the general population.

In both surveys, practices follow the same trends according to the age of the respondents. The hierarchy of beverages consumed on a weekly basis is, however, an exception in younger people, for whom wine is preferred to beer in the BSSM.

International studies partly corroborate these results, with reported tobacco use often lower in deaf or hard of hearing people than in the general population. This is particularly true of those whose deafness started early. The situation is more contrasted for alcohol [figure 4].

FIGURE 4 Comparison of the main indicators of psychoactive substances use between BSSM 2011/2012 and the Health Barometer 2010, according to age (%)



Sources: BSSM 2011/2012, Baromètre santé 2010, Inpes.

SEXUALITY AND RISK TAKING

Issues related to the sexuality of deaf or hard of hearing people have been little examined in French and foreign studies. Where they have been, they concern mainly sexually transmissible infections (STIs) associated with an increased risk of HIV transmission in deaf users of sign language, initially observed in the 1990s. These results reveal gaps as regards access to information, prevention and care.

In the BSSM, as in the Health Barometer 2010 in the general population, questions on sexuality were directed at people aged 15-54 years.

START OF SEXUAL ACTIVITY

Among those aged 15-54 years, nine people out of ten report already having had a sexual experience. The median age for first sexual relations, calculated for 15-29 year-olds, is 18.2 years for men and 18.4 years for women, i.e. more than 1 year later than in the general population.

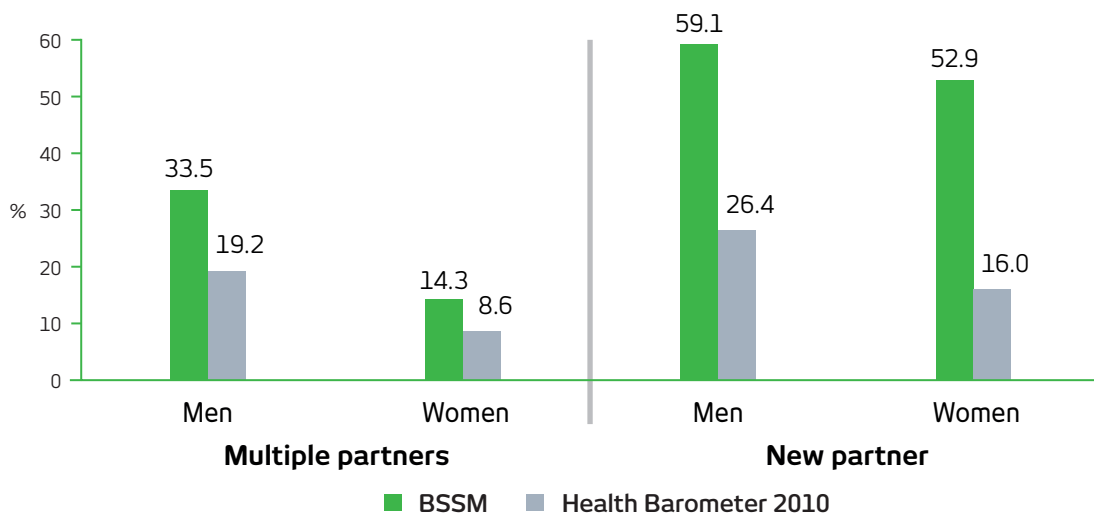
Among those aged 15-29 years who had already had sexual relations, 16.0% report having not really wanted their first sexual experience and 2.5% report having been coerced. Women more often than men reported not having wanted this first encounter (24.8%), i.e. twice as many women as in the general population.

MULTIPLE PARTNERS, NEW PARTNER AND CONDOMS

Having had more than one partner in the last 12 months is more commonly reported in the BSSM (one person in five sexually active in the 12 months) than in the general population. This is accompanied by a larger proportion of people who reported having had a new sexual partner in the last 12 months (51.4%) [Fig. 5].

Condom use with the new partner(s) is significantly less common than in the general population. Almost a third reported "never" having used one and only one third reported "always" using one.

FIGURE 5 Multiple partners and new partners in the last 12 months according to gender, among sexually active 15-54 year-olds during the year, in the BSSM 2011/2012 and the Health Barometer 2010 (%)



Sources: BSSM 2011/2012, Baromètre santé 2010, Inpes.

HOMOSEXUAL EXPERIENCES

The population of the BSSM is distinguished from the general population by more frequent homosexual experiences. In those aged 15-29 years, more than one man in six and more than one woman in thirty reported that their first experience had been shared with a person of the same sex. During life, 9.5% of men report having had exclusively homosexual relationships and 9.2% said they had relations with men and women (3.4% and 8.1% respectively in women).

SCREENING FOR HIV AND STIS

Among the sexually active people questioned, two thirds reported having undergone screening for HIV during their life. In men, this use of screening is markedly greater than that in the general population (62.2% vs 50.3%). Similarly, men report an STI in the last 5 years more frequently than in the general population (5.9% vs 2.0%).

CONTRACEPTION AND TOP

More than three quarters of women aged 15-54 years report using a means of preventing pregnancy, i.e. as many as in the general population. The breakdown of contraceptive methods used is itself different from that observed in the Health Barometer 2010. Fewer of the women questioned reported using the pill as the main method (43.3%), but more often use a condom (18.2%) or a local or natural method (8.9%). No difference is observed as regards use of the intrauterine device, which is used by a quarter of them, or new methods of contraception such as the patch, ring, implant or injection (2.9%).

More than one third of women who had already been pregnant reported having undergone a termination of pregnancy (TOP) during their life, i.e. 23.9% of all sexually active women aged 15-54 years, a higher proportion than observed in the general population (18.5%).

FUTURE PROSPECTS

In order to forestall and manage particularly striking states of psychological suffering in the BSSM sample, the main priority seems to be to consider:

- access to work and improving working conditions, which are strongly linked to states of psychological suffering;
- how to provide suitable treatments for psychological disorders and the risk of suicide;
- means of combating the experience of violence revealed by this survey.

Particular attention should also be paid to access to care and health information, above all for people who have difficulty getting hold of reading material, and to stepping up safer sex practices.

It would be worth carrying out secondary analyses and additional studies, particularly on mental health, violence and sexual practices, so as to consolidate these data and to further refine the research process.



For the full survey results, the specific methods used and the detailed bibliography, please refer to the following publication:
Sitbon A., dir. *Baromètre santé sourds et malentendants 2011/2012*.
Saint-Denis : Inpes, coll. Baromètres santé, 2015 : 296 p.
Online: <http://www.inpes.sante.fr/CFESBases/catalogue/pdf/1690.pdf>
(available in PDF format).