Surveying Populations with Disabilities

Specific mixed-mode methodologies to include sensory disabled people in quantitative surveys.

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Introduction

The starting point of this paper is to emphasize the absence of sensory disabled people in quantitative surveys - surveys among which the European Social Survey[1], which will be used as an example all along this paper. We will also choose our examples from Belgium, which is the country of the author.

What is the situation of the sensory disabled in Belgium?
In Belgium, the number of deaf and hard of hearing is estimated around 400.000 people (within 40.000 complete deaf). The complete blind are estimated around 20.000. This represents between 2.2% and 4% of the Belgian population.
Most sensory disabled live at home, not in institutions, as is the case for other disabilities (chiefly mental ones). Deaf and blind seem to be sociologically different. The deaf are a social group; they share a culture, a language and a specific identity (Mottez, 1987). They probably also share specific values, as our study will perhaps show it in the future.

So, this represents a rather big population but this population is nearly absent in general quantitative surveys. In French, there exist a few specific quantitative surveys (Pinon 2003[2], BSSM Study 2011[3]), which are very « disability » oriented, focused on limitations caused by disabilities and also emphasizing special needs of the disabled. There also exist a few surveys about sign language culture, but these are qualitative ones. But, as far as we know, not a single quantitative opinion survey exists for these people; as a first consequence, no

[1] The **European Social Survey** (the ESS) is an academically-driven social survey designed to chart and explain the interaction between Europe's changing institutions and the attitudes, beliefs and behavior patterns of its diverse populations.
Since 2001, the European Social Survey (ESS) has been mapping long-term attitudinal and behavioral changes in Europe's social, political and moral climate. It covers attitudes to religion, politics, moral issues and pressing policy concerns.
Currently gearing up for its sixth round, this is a biennial cross-sectional survey.

[2] "*Devenir des personnes sourdes. Enquête auprès des jeunes sourds de 18 à 30 ans » / « Future of the deaf. Survey on the young deaf from 18 to 30 years ».*

[3] "*Baromêtre Santé des Sourds et Malentendants*" / "Health study of the Deaf and Hard of Hearing".

comparison is possible with valid respondents in surveys about general opinions, values and attitudes.
In such surveys, as the European Social Survey, the disabled are technically excluded from the data collection. As a result, they are not taken into account in the statistical analyses that are based on these surveys.
The aim of this paper is to present and discuss some mixed-mode techniques to reach sensory disabled people and try to include them in general opinion surveys.

A question of fairness, a question of accuracy

In most of the better known quantitative surveys among individuals, a strict contact procedure nearly always leads to the exclusion of the people with a sensory handicap. If they live in institution, they will be considered as "*ineligible*"; if they stay at home they will be coded as "*mentally or physical unable to participate*". The consequence of excluding people with sensory handicap as "*ineligible*" or "*unable*" is double. At an ethical level, it means that they are not represented in the data collection and in the use of these data in opinion statistics. This could be considered as discrimination. At a methodological level, this absence represents a bias.

So, disabled people feel discriminated when results are extrapolated to the whole *Belgian* population. Let us make this clear with an example where a scientist (or a journalist) explains in an article or in interview that 87,1 % of the whole Belgian population agrees with the proposal "*Gay men and lesbians should be free to live their own life as they wish*[4]". Disabled people may find it not fair that this result is extrapolated to the whole Belgian population whereas they didn't participate in any way in the data collection. They really had no probability at all to participate. This is a weakness regarding the gold rule of the random sampling that says that everyone should have the same probability of being chosen to be in the sample. If it is not the case, at least this probability should be known in advance and obviously nonzero. Here again, the consequence of this weakness in the process could be considered both ethical and methodological. Are these people not really part of the Belgian population? Or is our method not good enough?

What is called public opinion is partly built on opinion surveys. And more and more so. There is a truly ethical problem in excluding a significant part of the population, especially in quantitative surveys concerning citizenship, democracy, social trust and every subject where

[4] ESS5-2010, Questionnaire, Question B30.

sensory disabled people could experience particular situations. Obviously, opinion surveys are not the only component of public opinion but, for the sensory disabled, it is one more discrimination that they are not included in the surveys, knowing also the fact that they are under-represented in media and in political life. This represents the first aspect of the exclusion of disabled people in quantitative surveys, that of "fairness".

In French, we usually say, for fun, that we try to make surveys « *plus juste* », because in French « *juste* » can mean « *fair* », but also « *precise, accurate, exact* ».
Moreover, it is highly probable that "*ineligible*" and "*non-response because of a sensory handicap*" are non-responses that are not "*at random*" at all. There exists a strong link between non-participation in surveys and the responses given to survey questionnaires. We may consider that there is a high risk that people with a sensory handicap (and especially deaf-dumb persons) will constitute a particular statistical group on some indicators that are used in opinion surveys.
Here we give an example of the situation encountered in a Belgian survey that we made in 2011. This research tried to apprehend the different aspects of participation to voting[5] and the evaluation of the electoral system in Belgium. Some qualitative interviews were done among non-respondents to understand the reasons of their "non-participation". Links were clearly established between participation to this survey and the responses to some questions. We were in a clear case of "missing not at random". If the electoral process is not suited to some specifics publics, such as disabled people for instance, neither are classic procedures for gathering opinions in quantitative surveys. We know that populations that are in situation of social isolation, such as disabled people here again, are more reluctant to cooperate, they are also harder to reach, but if even the mode of filling in the questionnaire is not adapted, participation to this kind of survey becomes the real "*mission impossible*" for disabled people. This is why we adapted in this survey, for the first time in Belgium, the questionnaire to several types of handicaps.

Psychological and sociological studies have often proved that there are differences between disabled people and non-disabled people on subjects like participation, citizenship, social inclusion (Thomson 2001), but also happiness and quality of life (Prilleltensky 2005).This is the core of some of the main questionnaires used in the large and better known opinion surveys (European Social Survey, World Values Survey, Eurobarometer, etc.).

[5] Fontaine 2012.

Of course, we know that the aim of large quantitative surveys is not to give information about particular groups. Our aim is not to integrate sensory disabled people in order to study these groups, but to reduce the non-response bias induced by the absence of these particular (statistically talking) people in standard survey procedures.
It is obvious that the new subsets of people with a sensory disability that will be obtained by classical random sampling will not be big enough to realize comparisons between these persons and valid ones.
But the techniques that are used here will also enable us to improve the specific quantitative surveys for these particular groups. They will also give the possibility of realizing quantitative surveys among sensory disabled in parallel with surveys among valid persons so as to compare both on some statistical indicators.

Concretely : in round 4 of the E.S.S. (2008), we counted in Belgium that 166 contacted person in the total gross sample were "*unable to participate because of mental or physical illness*"[6]. This represents around 5.7% of the total gross sample. We consider that a significant part of this category could take part in the survey if an alternative mode of filling in the questionnaire was proposed. In a perfect representative random sample the percentage of "sensory disabled" contact should vary between 2% and 4%, so we estimate that around half the "unable" should be able to answer an adapted questionnaire.

Specific mixed-mode adapted methods

The solution that we propose includes innovations either in the contact procedure, or in the mode.
Firstly, the contact procedure must be adapted to identify people with a sensory handicap and redirect them to an adapted procedure. If the result of the contact attempt is a contact, but no participation because the respondent is "*mentally or physical unable to participate",* another question is asked: "*Your opinion is very important for this survey. This survey exists in adapted versions for people with a sensory handicap: would you like to be contacted again thanks to an adapted procedure?*" Then, two questions about the kind of handicap and the access to a computer with internet are asked. This procedure allows the survey team to adapt and to send the appropriate invitation to the respondent with a sensory handicap[7].

[6] Calculated from the Belgian contact form files (ESS round 4).
[7] This redirection is a bit similar to the case of language barrier/redirection in the countries where several official languages exist, such as in Belgium.

For the deaf

An adapted version of the questionnaire has been setup. It is a web-based version that integrates videos of the translation of every question in sign language[8].

Why a sign-language web-based questionnaire?

Because every deaf cannot read texts. Written texts and words, as we usually use in questionnaires, are ways of communication that are built by hearing people. Because of the specificity of his way of communication, a deaf that uses sign language « *talks* » more with images and concepts than with words. Nevertheless, more and more deaf persons can read text. But "*reading deaf*" and "*non-reading deaf*" are not the same: age is the distinguishing variable. In Belgium, thanks to new techniques in specialized education as well as the massive use of new technologies (text message on mobile phones, email, Internet and especially social networks), young deaf people can more and more read texts.

However, long sentences, analogies, metaphors and other language games and effects remain really difficult to catch for most deaf people. We wanted not to set up a new bias by interviewing only the "*reading deaf*", who may be specific in their own subset (the deaf).

We have to be very careful to the risk of measurement error and that is why we were extremely careful and meticulous about the translation into sign language. We were inspired by the European Social Survey translation procedures that are used to translate the English source questionnaire into every concerned European language.

So two sign language interpreters translated from French into sign language and afterwards discussed the results. To follow the strict translation protocol and avoid the bias and translation effects, a deaf, who reads French text very easily, tested the video questionnaire. She compared sign language videos and text version of the questionnaire.

In most cases, the deaf respondent fills in the questionnaire online. Most of the deaf have adopted this technology and are able to fill in a questionnaire on their own. Nevertheless, not every deaf possesses a computer and Internet. Here again, age is the main distinguishing variable. So, for some deaf who don't want to, or cannot fill in the online version of the questionnaire, a specialized interviewer (most of the time a deaf himself) will meet the respondent and show them how to use the web-based "video questionnaire". We will call this person "sign language coach" in the following of this paper. In this case, the questionnaire is filled in using a laptop provided by the survey team.

No face-to-face interview in sign language is allowed because it would probably lead to some « interviewer bias », a kind of measurement error due to interpretation in sign language.

[8] See an example in annex 1.

Because of its nature, sign language cannot be written precisely. The translation, or more precisely the “interpretation”, has to be done from French every time, and that has to be done in direct. Some translations could vary depending on the time and the mood of the interviewer. With the video protocol, every translation into sign language is the same.
In the online questionnaire we have also included an audio player that “plays” the audio version of every question. This has been set up for the hard of hearing who use amplification devices.

For the blind

The web questionnaire, including sign language videos and audio version of the questions has been also adapted to the main vocal synthesis software used by the blind. Vocal synthesis software (sometimes also called “screen reader”) is software that reads (with a computer voice) every text in a web page, for example. It reads everything, indicates which link can be clicked, in which field you can write, where you can select items etc. Some blind, who are at ease with computers, use this software combined with adapted special keyboards with keys in Braille. In Belgium, we could observe that the use of computers is much less common among the blind than among the deaf. In addition, a blind person can answer a face-to-face interview, like any respondent. In some surveys, the respondent has to answer while using some “response cards”; these cards have only to be translated into Braille.
So, there are two possibilities for the blind: first, vocal synthesis and then, face to face interview with Braille “response cards”. Each of the modes has its advantages and disadvantages. Vocal synthesis is convenient and has the attractiveness of the autonomy, which is a very important issue for sensory disabled people, of course. But the time for filling in the questionnaire is up to five times longer than in face-to-face. Even if the web questionnaire is designed to be filled in several sessions, if the user has to have breaks, the risk of giving up is higher.
As it is the case for the deaf, not every blind has and can use a computer and is used to vocal synthesis. The blind that use vocal synthesis, or not, are not the same: age, economic means are distinguishing variables. A face-to-face survey is most of the time the best solution for the blind, even if they are often more afraid than other people of letting someone get into their houses.

Costs, Effectiveness and Conclusion

To conclude, what are the costs and effectiveness of the solutions and adaptations that are presented here?

Disability	Mode	Adjustment	Cost	Time	Effectiveness
Deafness	Web	Sign-video	+	+	☑
Deafness	Face-to-face	Sign-interviewer	+++	=	☒ (interviewer effect)
Deafness	Web help	Sign-language coach	++	+	☑
Blindness	Web	Vocal-synthesis	=	++	☒
Blindness	Face-to-face	Braille show cards	=	=	☑

As we have seen, for different disabilities (deafness and blindness) and different situations (people owning a computer or not), we can propose different modes and adapted procedures. Each one has its advantages and disadvantages. A supplementary very important aspect to integrate is the cost. In Belgium, graduated and official sign language interpreters are very rare. The translation into sign language is also a very hard and exhausting exercise. For these reasons, it is not conceivable to train special interviewers who know sign language to face-to-face surveys[9]. Hiring a sign language interpreter team and making videos that can be used on a web questionnaire represent a much more reasonable cost.
For the deaf, we advocate to choose between "*web*" and "*web with a sign language coach*", depending on the situation of the respondent.

The idea of using a web questionnaire with vocal synthesis for the blind is tempting, because costs are very limited, but it does not seem to be adapted because of the time needed for filling in. For the blind, we recommend to send an interviewer (with a special training for this particular situation): this will cost about the same as a "classical" face-to-face interview.

To conclude, our specific mixed-mode adapted procedures tend to prove that, with reasonable costs, it is possible to include a large part of the sensory disabled people in general quantitative surveys. In our future works, we will try to measure the reducing of the specific non-response bias, which is one of the two major issues of our project, the

[9] It is also not desirable, because of the risk of bias due to the interviewer effect.

methodological one. The ethical issue is also the center of our concern and the currently tested techniques should contribute to a fairer use of the quantitative surveys and of inference. This contributes, in a certain measure, to promote inclusion of disabled people into public opinion and, as a result, into democratic society.

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Annex 1.


European Social Survey
Enquête Sociale Européenne [Round 6]
L'Enquête Sociale Européenne est une enquête scientifique menée par les universités et les bureaux d'études d'opinion dans plus de 25 pays européens. Le but de cette enquête est de connaître l'opinion de personnes de différents pays à propos de différents sujets. Cette année, pour la première fois, une version adaptée aux personnes ayant un handicap sensoriel a été mise en place pour permettre à tous de participer. C'est pourquoi il est important que nous connaissions également votre avis.
0%
100%
Dans l'ensemble, dans quelle mesure êtes-vous satisfait de votre vie actuelle ? Utilisez cette échelle s'il vous plaît, où 0 signifie tout à fait insatisfait et 10 tout à fait satisfait ?
La question en langue des signes [Vidéo]
partager
En savoir plus
La question en audio
Veuillez sélectionner une réponse ci-dessous
0 : Tout à fait insatisfait
1
2
3
4
5
6
7
8
9
10 : Tout à fait satisfait
Ne sait pas
Sans réponse