

«Design for All» in Social Research on Persons with Disabilities

«Diseño para todos» en la investigación social sobre personas con discapacidad

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Key words

Disability • Surveys
• Research Methodology • Information Sources • Sampling
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Palabras clave

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Abstract

Social studies on disability have increased in number and importance in Spain and other countries over the last few years. Nevertheless, the majority of the available sources and studies do not adequately represent this heterogeneous group, which currently makes up about 9 per cent of the Spanish population. The implementation of social measures requires representative sources and studies containing relevant information. The aim of this paper is to identify the main difficulties involved in designing and developing social research methods concerning persons with disabilities, and offer proposals and recommendations in order to advance towards a more inclusive social research using the concepts of accessibility and design for all.

Resumen

Los estudios sociales sobre la discapacidad han aumentado en número e importancia en España y otros países durante los últimos años. Sin embargo, la mayoría de fuentes de información y estudios disponibles no recogen de manera adecuada la realidad de un colectivo muy heterogéneo, que supone en la actualidad aproximadamente el 9 por ciento de la población española. La implementación de medidas sociales requiere de fuentes y estudios representativos que aporten información precisa acerca de estas personas. El objetivo de esta nota es identificar las principales dificultades que se plantean a la hora de diseñar y llevar a la práctica metodologías de investigación social adecuadas hacia las personas con discapacidad, así como ofrecer propuestas y recomendaciones para avanzar hacia una investigación social más inclusiva, mediante los conceptos de accesibilidad y diseño para todos.

INTRODUCTION¹

The results of the Survey on Disability, Personal Autonomy and Dependency Situations show that in 2008 there were 3,847,900

people in Spain with disabilities in households and 269,400 residents in centres, which together make up more than four million people, approximately 9% of the population (INE, 2008). Despite their significant presence in the

¹ Work carried out as part of the framework of research projects: “Qualitative Tracking with Young Disabled in European States. Quali-TYDES” (European Science Foundation, 09-ECRP-032). “Hidden Innovation: paradigm shift

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country's demographics and major advances in the recognition of their rights, there are still many barriers that prevent persons with disabilities from leading a full social life and participating on equal terms in the same activities as other people (UN, 2006).

Social sciences have only recently started to focus on persons with disabilities. Reasons for the lack of social research on disability not only lie in specific difficulties related to studying this group, based on their functional characteristics, but also inadequate research methods. Examples of this include the use of self-administered questionnaires, which results in people who cannot read them being excluded from the research, conducting focus groups in locations inaccessible to people with reduced mobility or telephone interviews that exclude those who have difficulty hearing.

The lack of information resulting from such procedures heightens the social invisibility of persons with disabilities; their situation is not taken into account in public policy so it is not known, and it is not known because no reliable, consistent information is produced on it (SEREM, 1975; UN, 1982, 1993). These difficulties highlight the need for specific research on persons with disabilities, and for this group to be represented adequately in research carried out on the general population (UN, 1996, 2001).

This paper proposes a reflection on the need to design and implement social research methodologies that properly include persons with disabilities. To this end, illustrative examples of difficulties and barriers in studying this group are set out, while, based on previous experiences and the recommendations of international organisations and disabled people's groups, proposals are made for improving this field of research. These proposals arise from the viewpoint of something we consider novel: consideration of these difficulties and barriers from the perspective of the concept of "accessibility" and application of "design for all" to social research instruments and phases.

DISABILITY AND DESIGN FOR ALL

Traditionally, efforts to combat discrimination due to lack of access have focused on the elimination of physical and architectural barriers that limit activity and restrict the social participation of persons with disabilities. However, a broader and more universal vision of accessibility requirements has been developed over the past decade in order to eliminate all types of obstacles and barriers (Spanish Law 51/2003, UN, 2006). Aspiration towards greater accessibility has led to strengthening the idea of "design for all" or "universal design" (García de Sola, 2006; Ginnerup, 2010). Design for all aims to take into account, in the design phase itself, accessibility requirements arising from people's different types and degrees of functional capacity. Not meeting this objective in design processes inevitably causes discrimination, exclusion and social participation problems for many groups (European Commission, 2001; European Institute for Design and Disability, 2004).

For example, for a person using a wheelchair, an accessible lift should have a door wide enough and buttons at the proper height; for someone with limited vision, that same lift should have a Braille code on the buttons and a recorded announcement of floors; for a person with intellectual disabilities, easily understandable pictograms should be provided; and someone with hearing impairment should be provided with signalling devices, information in sign language, etc. If all of these design elements were present, this lift could be said to be accessible (and therefore not exclusive) to all types of users considered.

Often when designing methodologies, techniques and instruments for social research, an average person with standard functional capacities is considered as the target user. However, this type of average person does not exist, but is rather a statistical fiction resulting from the calculation of many non-

standard people (IMSERO, 2004). This means that a significant part of the research methods, techniques and instruments commonly used in social sciences does not include accessibility and inclusion characteristics resulting from the “design for all” practice.

SOCIAL RESEARCH ON PERSONS WITH DISABILITIES

Empirical studies on disability have increased considerably in recent years (Abela et al., 2003). In most countries, this research has been dominated by a quantitative approach (Hartley and Muhit, 2003), accompanied by an implicit consideration of persons with disabilities as a homogeneous group, which has yielded excessively general results. Perhaps that is why public policies have historically treated persons with disabilities as a single group, failing to develop specific social measures (Horejes, 2007).

In terms of qualitative research, only in recent years have we started to hear stories and proposals directly from disabled people. It has been argued that the development of qualitative research has helped put persons with disabilities on the research agenda and promote such studies in many countries worldwide (Hartley and Muhit, 2003, Ramcharan and Grant, 2001). At present, social research increasingly relies on direct testimonies to gain a better understanding of the experiences and living conditions of these people (Horejes, 2007).

In Spain, there have been three surveys over the past 25 years that have helped fill in the gaps and provide the basic statistical reference on disability and dependents: the Survey on Disabilities, Impairments and Handicaps (EDDM), 1986, the Survey on Disabilities, Impairments and Health Status (EDDES), 1999, and the Survey on Disability, Personal Autonomy and Dependency Situations (EDAD) in 2008. Despite the large sample and broad representation of these sur-

veys in Spain (and partly due to changes in the conceptualisation of disability), the results of these three surveys are barely comparable with one another and do not provide an accurate insight into the evolution of the phenomenon (Jiménez Lara and Huete García, 2010).

Although there has been an undoubted increase in information available, there is still a lot of ground to be covered in this field. It has been argued that the sociology of disability lacks, not only in Spain but also in other countries, a consistent theoretical thread and, therefore, an empirical foundation (Ferreira, 2008). Two of the most important gaps in this field are: (a) the lack of minimally disaggregated information on disability (type and degree of difficulty to perform activities of daily living) in most general population surveys; and (b) the low representation of persons with disabilities in these data sources. These gaps are clearly noticeable in surveys and records that serve as reference to build indicators on Spain’s economic and social reality. It is also common to find theoretical studies without empirical support, in which a certain disability prevails over others, where basic terminological confusions occur or where there is little methodological rigour (Aguado, 2001).

THE APPLICATION OF SOCIAL RESEARCH METHODS TO THE STUDY OF PERSONS WITH DISABILITIES

Here we review the main phases of a standard social research project in relation to the study on persons with disabilities. Some of the difficulties presented are found in most social research studies, but are more prominent amongst these groups. In these cases, the actual design of the research techniques and instruments to use often requires certain adaptations. According to the aforementioned approach, such adaptations are the ‘reasonable adjustments’ needed to ensure,

through the application of design for all, the non-discrimination and equal rights and opportunities of these people (Spanish Law 51/2003, De Asís et al., 2005; UN, 2006).

Research design

Most social research methods are designed to analyse the reality of persons without disabilities, so their results obscure the reality of an important part of society: persons with disabilities. Various theoretical-methodological positions point to the need to involve study participants (and potential users or beneficiaries of their results) as much as possible in the research process. This helps to obtain reliable, useful results for effectively improving group situations (Alberich, 2000:70).

These types of methodologies for the social study of disability have been conceptualised in the English-language literature as 'inclusive research', and applied more frequently to groups with cognitive disabilities (Gilbert, 2004; Walmsley, 2004). In these studies, persons with disabilities participate in all stages of the research process, from the initial definition of goals to the drafting of the final report and dissemination of results, and may also be involved in managing and leading the process (Boland et al., 2007).

Apart from their advantages, based on their flexibility and action-orientation, these methods make it more difficult to generalise their results (less validity and representativeness) and entail a more complex research process, which usually requires more time and resources. However, if the research aims to effectively include persons with disabilities, they must be provided with the economic and material resources required to overcome all possible barriers to participation. In this respect, a need has been highlighted to adapt research times and schedules for persons with intellectual disabilities, pay them the same as other researchers and guarantee that the results are validated by them (Van Hove, 1999).

Sample design

There are two basic obstacles to the preparation of reliable sample designs representative of disabled people. The first is incomplete knowledge of this population's universe and its very dynamic and changing reality. Other shortcomings include no availability of a census on persons with disabilities; although there is information from the above-mentioned surveys, these are not conducted often enough.

The second obstacle is that different definitions of the concept 'disability' are often used. Although the definition of disability has a common theoretical international reference in *International Classification of Functioning, Disability and Health* (WHO, 2001), conceptualisations are different, sometimes contradictory, when applying social research techniques.²

On the other hand, sociological studies on persons with disabilities tend to include, and over-represent, in the sample design:

- a. People not socially and/or geographically isolated. Undetected people cannot be captured for the study and are therefore not represented in the sample.
- b. Organised people or those close to organisations that have overcome the social stigma of being disabled and who have cultural baggage associated with the target group ('group culture'). In this regard, some disabled people have expressed

² For example, the EDAD Survey in 2008 contained 44 questions on daily living activities, such as: "Do you have significant difficulty walking or moving around your home without help or supervision?" (INE, 2008). Only one affirmative reply to any of these 44 questions results in the person interviewed being considered a "disabled person". In the National Health Survey of 2003, people were identified as disabled if they answered the following question affirmatively: "Do you have any difficulty carrying out activities of daily living (going out, dressing, washing, eating, etc.)?" (INE, 2003). If both surveys had been given to the same population, they would have generated very different samples of disabled people, both in terms of size and composition.

their feelings of annoyance about having been repeatedly contacted as “guinea pigs” for research in this field (Technosiste, 2007).

- c. People with “recognisable” disabilities. The sample selection process (e.g. through the ‘snowballing’ technique) usually over-represents disabilities easily identifiable by family members, service providers, neighbours and even by the people with the disability themselves. The under-representation of people with less visible disabilities occurs because their existence is unknown or because the definitions of experts and the beliefs of the general population do not coincide. Examples of this might be schizophrenia or bipolar disorder.

Normally, the variables used as criteria for the sample design are sex, age, marital status, educational level and relationship with economic activity (Alvira, 2004). An important socio-demographic characteristic such as disability should not be excluded from social research instruments, not only to determine its prevalence, but also to analyse it in relation to the rest of the characteristics considered. A first step would therefore be to introduce different types of disability as a design criterion (stratum or quota).

The design of a qualitative study sample also faces the obstacle of achieving an appropriate balance between the homogeneity and heterogeneity of participants (Castro and Castro, 2001), which is especially sensitive for persons with disabilities. An example of this is deaf people, whose discourse in a group may be as rich as or richer than that of a group made up of non-deaf people, but which has difficulties in communicating with the latter due to the use of different languages. In contrast, the greater complexity of the sample designs for developing heterogeneous groups in their functional characteristics opens up the possibility of obtain-

ing unexpected and different results, which may be important and have a wider application: common or different needs and demands, viable solutions for various types of common or different disabilities, etc.

Research techniques

In addition to the usual considerations on designing this technique (simple questions, closed questions, self-excluding questions, interviewer training, etc.), producing a survey for the disabled population requires additional adjustments:

1. The length and duration of the questionnaire must be limited. It has been shown that lengthy questionnaires significantly affect the rate of non-response (Cruz, 1990), a relationship that is more pronounced in persons with disabilities (e.g. with difficulties in understanding the questions, completing the questionnaire directly, communicating their responses, etc.).
2. The questionnaire must be written in non-discriminatory language.
3. For people with cognitive disabilities, questions and response categories must be simplified as much as possible. For example, instead of asking, “How satisfied are you with your life (very satisfied, satisfied, dissatisfied or very dissatisfied)?”, ask the question more directly and simply: “How do you feel today?”. One possibility is to use visual references as examples of categorisations, which might be particularly useful when there are more than two response options. In addition to the written categories, the interviewee is offered icons that allude to each of them, making it easier to identify the intended response (Boland et al., 2007).
4. Sensitive questions (e.g. on health issues, government grants, etc.) should not be placed at the beginning of the

questionnaire, as they may lead to suspicion and defensiveness, generating false or evasive answers (UN, 2001).

5. If possible, the questions should be formulated to avoid questioning the capacities of the person interviewed. Instead of asking, "Are you able to use a mobile phone?", the question, "Do you consider that the design of mobile phones is appropriate?" should be formulated.

Field work

An implicit goal of any inclusive social research should be the possibility of all people in the sample, regardless of their functional characteristics, being able to participate in it on an equal basis and provide information accordingly.

The practice of design for all should be present from the contact phase, adapting communication channels to the target population's functional characteristics (Technosite, 2007). For example, for people with intellectual disabilities, prior contact may be necessary with the tutor or an available professional, while people with hearing impairment should be contacted by ordinary mail or e-mail. Given that many persons with disabilities face physical barriers to participating in studies, the accessibility of the study location must be guaranteed. Holding a discussion group made up of people with reduced mobility may require providing adapted transport to the site where the technique is applied, or the use of electronic resources (e.g. virtual discussion group).

Sometimes interviewers are not suitably prepared to communicate with persons with disabilities, either due to lack of specific training (e.g. no knowledge of sign language) or because of not knowing how to relate to these groups correctly. Quite often in face-to-face interviews, the interviewer avoids interviewing or putting the questionnaire to anyone they think might slow down their work or not answer the questions properly

(UN, 2001). These training and attitudinal barriers must also be considered and appropriately dealt with. Therefore, interviewer training and awareness must be considered as an essential aspect in studies that aim to be inclusive and representative of persons with disabilities.

One possibility is people from the target population conducting the interviews or leading the groups themselves (Harris and Roberts, 2003). This is a way to ensure that the interviewers are aware of the situation of the interviewees, facilitate discourse (due to empathy) and eliminate any biases from the expert's gaze. In contrast, this option may entail a certain degree of self-censorship, as it may force interviewees to articulate dominant discourses in their group (demands, complaints, etc.).

In quantitative social research on persons with disabilities it is common to use "proxies" (relatives, friends or acquaintances who act on behalf of these people). This was the procedure adopted in the three aforementioned major surveys conducted on this matter in Spain. Although in many cases the use of proxies is unavoidable, there are drawbacks. Apart from ethical problems arising, uncertainty is also generated over the validity of the information (Todorov and Kirchner, 2000), since it does not come directly from the person in the study, but rather from an agent who interprets, with more or less accuracy, that person's experiences, opinions and/or beliefs (Ramcharan and Grant, 2001).

With regard to survey research, reasonable adjustments aimed at achieving equal opportunities for those involved in it may require specific measures for each type of disability:

- a. *People who have difficulties using their hands* will require a person to help them complete it, or additional technical aids to enter information on accessible hardware or software. In any case, the face-

to-face questionnaire carried out by an interviewer is perhaps the most reliable method, as it can be used while conducting the survey and to clear up any doubts that arise (UN, 2001).

- b. The use of a questionnaire aimed at *people with visual impairments*, if self-administered, should include questions and answers adapted through the Braille system of reading and writing, recording and/or hearing. Whether the interview is by telephone or face-to-face, the questionnaire must be simple and avoid questions that require reading the responses. Interviewees should also avoid having to memorise various possible answers.
- c. For *people with hearing difficulties*, one option may be to administer the questionnaire by e-mail or on a website, although if these procedures are used the information of those who do not own or use such tools will be lost. If the face-to-face questionnaire is chosen, interviewers must know sign language.
- d. The survey involving *people with mobility problems* must avoid them having to leave their usual environments (home or work); if this is not possible, adapted means of transport must be provided free of charge to participants.
- e. For *people with intellectual or cognitive disabilities*, the most appropriate method is also the face-to-face interview which, in contrast to the telephone, makes it possible to show cards and complete the information collection process more simply. The use of photographs has proven to be very useful, directly situating the interviewee at the heart of the research and guiding their responses more accurately (Young, 2006).

In relation to qualitative techniques, the main barriers arise from participants' communication and expression difficulties (verbal, written, gestural, etc.). In interviews with

people who have difficulties understanding concepts or expressing ideas, formulating questions and developing the conversation (suggestions and provocations) must be adapted to the participants' abstraction capacity. Alternative channels can be used for this purpose, such as written expression in specific cases and different languages to normal languages to enable their expression, such as painting, sculpture, body language, etc. (Boland et al., 2007).

For people with hearing impairment, it is advisable that interviewers or group leaders fluently speak sign language and have experience in dealing with this group. If the group or the interview is held with people who tire easily, breaks should be provided or the technique cancelled and/or postponed if necessary (Harris and Roberts, 2003). Apart from harming the interviewee, tiredness can result in skewed information.

Finally, during field work it is important to treat interviewees in the right manner, something which is not always achieved. Although this is a general principle for applying these techniques, sensitivity and anticipation must be greater still for persons with disabilities. The right criterion is empathy: "What is normal is to treat people normally" (Technosite, 2007). In short, all mechanisms that enable respectful, free-flowing communication and a correct interpretation of discourses must be articulated.

CONCLUSIONS

The design of goods, products, environments, processes, services and activities in general often ignores the specific needs arising from the functional characteristics of persons with disabilities. As a result, discrimination due to disability is experienced by millions of people every day (UN, 2006). In the field of social research, this work has shown how the inadequate design of study methodologies, techniques and tools can

significantly restrict the participation possibilities of persons with disabilities, resulting in the inadequate compilation of basic and necessary information on their personal and social reality.

In our opinion, there are two main challenges that disability-related social research must tackle: firstly, since many general population surveys repeatedly ignore these people, there is a need to improve the quality of methodological designs and hence the validity and reliability of research results. Therefore, sample designs must be prepared in such a way as to include aspects of disability in general population information sources, and ensure the representativeness of persons with disabilities. Furthermore, the requirement of including, as far as possible, the voices of persons with disabilities is unavoidable, and therefore it is necessary to develop methodological and instrumental designs that help eliminate all possible participation barriers, and adopting any additional resources necessary.

Applied sociology can and should benefit from the ideas of universal accessibility and design for all adopted in other fields (Spanish Law 51/2003, IMSERSO, 2004, Spanish Law 14/2011, art. 2 and 33). Social research designed to fully include persons with disabilities will help increase the quality of studies, not only for these people but also for the general population. From this inclusion-oriented perspective, social research results may serve as a useful information base for public policy to contribute to the integration and full representation of persons with disabilities in all areas of society.

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