DISABILITY AND CENSUSES: METHODOLOGICAL CHALLENGES AND EXPERIENCE IN MEASURING DISABILITY

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ABSTRACT: The present article has the primary objective of displaying stances about the role, the reach and limitations of a Census as a means of collecting data on disability in different countries. It will present the purpose of the Recommendation from the Washington Group on Disability Statistics in the context of introducing disability-related questions in national censuses from the year 2010 onwards. Furthermore, the article will inspect the limitations regarding measuring disability and functional difficulties through the means of a census, relying on the experience from other countries and scholarly research. This part will strongly focus on the formulations made by the Washington Group on Disability Statistics and the set of short questions presently used in national censuses. Finally, the article will briefly observe the experience from the Serbian national census in 2011 in measuring functional difficulties for the first time.

KEYWORDS: measuring disability, census, methodology, survey

INTRODUCTION

In the year 2001, an international gathering, organized by the United Nations, officially recognized an urgent necessity to reach a methodological structure in measuring disability that would ensure wide application throughout the international community and provide internationally comparable data on disability of populations in national censuses [Madans et al. 2011].

Consequently, the Washington Group on Disability Statistics was formed, as an expert body under the umbrella of the UN, comprising of experts from national statistical offices, NGOs and disability organizations. Its main objective and function was defining 'disability' for the purposes of comparable

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1 The present article is to be attributed as a result to the project No 179023, financed by the Serbian Ministry of Education and Science.
measurement, developing methodology that was simple and applicable in diverse national contexts and culturally neutral. The Group was to achieve precise recommendations concerning measuring disability in national censuses, therefore ensuring as wide as possible application in the member countries of the UN [Madans et al. 2011].

Recommendations of the Washington Group. The result of the Group’s work on finding a set of questions that would address functional difficulties/disabilities throughout a nation was a group of six short questions that aim at the basic living performances or actions. These include sight, hearing, walking, memory/concentration, independence in self-care and communication. These were included in the Recommendation that was to influence national censuses occurring around the year 2010.

Six short questions are very simple. They require answers on the presence and severity of difficulties in the given areas, as seen by the census interviewee. The given answers are an indication of disability, i.e. if a person reports serious difficulties or total incapability in a certain area, he or she would be considered a person with a (particular kind of) disability in the census data.

The questions formulated by the Washington Group have the objective to ensure international comparability between populations from different cultural, traditional and economic conditions, by focusing on basic functions and areas. These functions have been chosen in accordance with the principles of simplicity, conciseness, universality and comparability. There is a presumption that these areas represent the space where the limitations of participation most usually occur [Mont 2007].

Limitations of the proposed methodology. The present article addresses some of the main issues that could be seen as limitations or shortcomings of the WG methodology for measuring disabilities. Some of them are not only caused by such an approach, but are resulting from the census methodology itself. These issues must be taken into account when using census data as a source for analysing the status of persons with disabilities in a given context.

Perceiving disability. The questions foreseen to identify disability in census activities are not identity-related. Whereas many other methods outside the census methodology would base themselves on personal identification of an interviewee (“Do you perceive yourself as a person with disabilities?”), these census questions do not aim at identifying the number of people in a single country (or on a lower level) who think of themselves to be a person with a disability, since that particular term is indeed very subjective, followed by a serious level of stigma, misunderstanding or misuse. Their aim is to indentify persons who perceive their own functioning as limited, and to derive from that a number and structure of people who are heavily or entirely unable to function in certain basic areas of life. The label used for that purpose is ‘persons with disabilities’. The main method is therefore not identifying oneself as a person with disabilities, but self-reporting on personal health restrictions and functional difficulties.

Identifying social interaction and inclusion. The methodology set out by the Washington Group does not dive into the issues concerning the influence
of the reported difficulty on a wider course of life of the interviewee, the level of social participation and their inclusion in a society. Even though it was possible to create such an approach, it would have been challenging and somewhat contrary to the overall aims in at least two ways. First, the form in which a census is performed and the structure of the census sheet itself do not allow for open, detailed or very specific questions that are solely based on the subjective perception of the interviewee. Therefore, the set of six short and basic questions were considered a more appropriate solution. Second, such an approach would compromise and potentially undermine the international comparability of the census data [Mont 2007].

If one is to reach conclusions on the levels of social interaction, inclusion and participation of persons with disabilities that are based on census data, further analysis is in order. Namely, only through cross-analysis between the data obtained in chapters concerning education, employment and labour, means of support, etc. will one be able to put information on disabilities/difficulties in context and perspective. The main approach to this regard is making a differentiation between the values and data found in the population with and without disabilities (or general population as an alternative).

Identifying groups and types of disabilities. It was the Washington Group itself that pointed out quite explicitly in their Recommendations that there are obvious and anticipated limitations to the given methodology of measuring disability through census activities [Washington Group, 2008]. It is a sort of general identification of disabilities that this methodology is aiming to achieve, recognising the large group of persons whose functional capacity is perceived as limited or non-existent, certain obvious limitations result from such objectives, particularly in regard to specific types of disability.

Namely, as stated above, six question address six basic functions (areas) – sight, hearing, walking, concentration (memory), self-care and communication (ability to understand and be understood). This would practically mean that disabilities regarding walking (physical disability), hearing and seeing are easily detectable according to the census data. Where the problem occurs is in identifying persons with mental disabilities – intellectual and psycho-social impairments [Washington Group, 2008]. The Group has underlined that it should not be expected from the given methodology to perform identification by types of disabilities as we know them. There are several reasons for this and we will name only a few. Firstly, the methodology itself offers criteria for identifying disability – only persons reporting higher level of difficulties are considered persons with disabilities. Moreover, the methodology also offers descriptive illustrations of difficulties, explaining who and what should go under the umbrella of disabilities in the census data.2 The problem in identification occurs due to the fact that certain descriptions of difficulties in the methodological instructions for census interviewers are vague and too inclusive. For instance, a person shall have a difficulty in communication or under-

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standing if any of the many stated causes is present (brain damage, severe speaking difficulties, intellectual impairments, non-cummmunicative state, etc.). In practice, this would prevent us from being able to identify a specific cause or type of disability in a population group based on the census data, since in that very group we would find people with several different types of impairment, functional difficulty or health problem, or those who are simply harder to understand through usual means of communication. Almost the same problem can be found in the category of persons with difficulties regarding concentration and memory. As a result, particular groups of persons with intellectual and psycho-social disability are the hardest to identify through census data, because they appear to get “lost” in the larger groups. Also, another problem with indentifying these specific types of disabilities could be in the unwillingness to report them in direct interviews, as a part of census activities, due to the obvious burdens of labels and social stigma. Therefore, the census data on disability is least accurate when it comes to detecting groups of people with difficulties related to mental health issues [Mont 2007].

As Mont [2007] noted, there are four common questions or areas when addressing difficulties in the mental health area of functioning in screening activities over a population – learning, making decisions, memory/concentration and understanding. For census purposes, the Group chose to use the latter two, due to the reasons of pragmatism, efficiency and cultural universality of meaning (the former two could differ in meaning across regions).

To conclude, although the given methodology offers solid grounds for general identification of disabilities of all kinds, it leaves a significant gap in identifying persons with mental disabilities. It can often result in overlapping between intellectual, psycho-social and other disabilities, and it focuses only on some of the aspects and dimensions that mental disability as a whole might include. At the same time, persons with mental disabilities remain the most marginalized, ignored and the least participatory of all the groups of people with disabilities [Marković 2012].

Answering the census questions – original and proxy answers. When we approach analysing and evaluating data obtained through census activities, the difference made by those who gave the answers to the census questions on disability and functional difficulties could be of a particular relevance in measuring disability.

Namely, a high possibility exists that a person with certain difficulty will be incapable or more likely considered incapable by others (family member, care-giver, etc.) of answering the census questions herself. Therefore, it might happen that another person answers questions on the levels of difficulties and disabilities on behalf of the person in question, and the census methodology usually allows it.

Again, such a possibility is higher in cases of persons perceived as having a difficulty in the area of mental health than in other cases. It can be seen as a result of technical issues (lack of time to communicate adequately with people whose means of communication is slower or unorthodox), social and other presumptions or stigma, and general prejudice.
Whatever the reason may be, this doing could influence the end result. There are some authors\(^3\) who illustrate findings that support the possibility that the results concerning disability occurrence and other disability-related data in census are directly influenced by the ones who gave the answers to the questions, i.e. whether the answer-giver was the person with a disability or someone who acted on their behalf.

This particular phenomenon also plays a relevant role in measuring disability through census in institutional surroundings. In practice, it should be expected that the interviewer or the statistical office does not perform full and precise census activities (interviews) with each resident at a psychiatric institution or residential institution for persons with disabilities, for instance. Even though the human rights standards require full enjoyment of all rights and full equality and respect for every person with disabilities, in reality most of the institutions shall fill in the given census forms without even communicating it with its residents. As a result, we could encounter thousands of census forms with answers on disability that did not even come in contact with the person in question. Such a scenario undermines the 'social model' that underlines the methodology of disability measurement and could impair the final results to a large extent, when it comes to people with disabilities living in residential contexts. It also contributes, as a practice, to the ongoing objectification of persons with disabilities, especially those who do not live in a community but in secluded and/or closed institutions.


Since the continuous data on disability is non-existent in the Republic of Serbia, the census data on persons with disabilities could be used as a primary source of such information, with all the reservations that the use of census data impose, due to the reasons given in the previous sections of this article.

The author of this article has been appointed the sole author by the Statistical Office of a study focusing on census data on disability in Serbia. The book in question performs the needed combining of different data regarding main aspects of social and personal functioning of persons with disabilities in Serbia based on census data, and reveals the relevant information on persons with reported difficulties for the first time in Serbia.

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**ОРИГИНАЛНИ НАУЧНИ РАД**

**ИНВАЛИДНОСТ И ПОПИСИ СТАНОВНИШТВА: МЕТОДОЛОШКИ ИЗАЗОВИ И ИСКУСТВА У МЕРЕЊУ СТЕПЕНА ИНВАЛИДНОСТИ**

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РЕЗИМЕ: Овај чланак има за циљ да, пре свега, прикаже становишта о улози, достигнућима и ограничењима једног пописа становништва као начина да се прикупе подаци о инвалидности у различитим земљама. Чланак ће приказати изузетна јединица инвалидности као уметност и као предмет националне пописе од 2010. године на овамо. Надаље, чланак ће испитати ограничења која се односе на мерење степена инвалидности и функционалних смешти по попису, а све ослањајући се на искуства из других земаља и научних истраживања. Овај се део посебно фокусира на формулирање које су извели у Вашингтонској групи за статистику у области инвалидности, као и на изузетне смешти које се средиштем користе у националним пописима. На крају, рад ће укратко да се осврну на искуства из националног пописа у Србији у 2011. години, а у вези са мерењем функционалних смешти по први пут.

КЉУЧНЕ РЕЧИ: мерење степена инвалидности, попис, методологија, истраживање