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Disability in the Capability Space

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Abstract

This thesis presents an analytical framework for conceptualizing and assessing well-being of people with disabilities within a multidimensional understanding of disability. It discusses different models of disability and shows how, by looking at disability at the capability level, it is possible to overcome the limits of the previous models, such as: medical, social and ICF model.

This thesis discusses the relevance of incorporating a capability perspective in disability studies and provides a dynamic conceptualization of disability among a specific type of people with disabilities in Modena. Following a multidimensional concept of well-being, the methodology used comprises a cross-sectional and a multidimensional analysis of people with disabilities well-being using data collected from a new dataset—the Blind—Disabled Capability Survey (BCS). The results point to the importance of various factors that contribute to enhancing people with disabilities capabilities and policy actions, such as the interaction between means and individual ability, opportunities, freedom of choice and policy responses.

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1. Background

1.1. Introduction

Disability is a complex and multidimensional concept not only because it is difficult to measure but also because it does not exist a commonly accepted definition among researchers of different disciplines, which causes a choice among fragmented and alternative paradigms. Indeed, for long time disability has been seen just from a singular aspect either medical or social, which in turn implied the use of actions mainly addressed to medical care or reorganization of social environment. Nevertheless, recent concerns about its definition and measurement have raised a number of critics on both a theoretical and analytical level, which eventually have led to a reconsideration of the previous paradigms.

To this end, as far as we are concerned with the effect of physical/mental disability on people's lives, we consider of relevant importance to investigate it within a new conceptual framework where a central role in determining the interaction between individual, environmental and social characteristics is played by people's choices.

Nevertheless, in spite of the fact that disability is an important welfare concern, socio-economic studies on the effect of disability on human well-being are quite limited. This thesis seeks to fill this gap by showing the incidence of people choices, individual and environmental characteristics, and social opportunities on well-being of people with disability, seen as capability enhancement. Furthermore, in order to highlight the relevance of individual choices for efficient policy-maker decisions, we describe how an assessment of well-being that does not take note of this aspect can lead to an inefficient public spending.

Therefore, with the purpose of understanding disability and its relation to human well-being, this study deals with a number of challenging aspects, which rely upon both theoretical and empirical aspects.

The first set of issues involves the use of a broad framework to define disability and a clear conceptualization. The conceptual model we use here is based on Sen's Capability Approach (CA) and deals with the idea of assessing and enhance people's capability sets by referring to a phenomenological analysis of available opportunities and freedom of choice of people with disabilities.

The second set of problems is more methodological and includes the elaboration and development of a robust informational set together with appropriate mathematical tools. To this end a Blind Disabled people Capability Survey has been developed. The Blind-Disabled people Capability Survey (BCS) allows a measure of individual's capability set, resulting from a combination of key information on actual achievements and ability to achieve in terms of both freedom and opportunities.

The BCS assesses the opportunities and the freedom of choice a person, with disability, has in a given socio-environmental context, with the aim of identifying where the lack of achievements belongs to individual choices or lack of opportunities. In particular, this study aims to shift the focus from the specificities of the disabling situation, to an assessment of equality in terms of possibilities and choices.

Using data collected in 2010 with a local survey in the city of Modena, we assess blind and partially sighted capabilities besides estimating the relationship between disability and well-being as captured by multi-level subjective judgment and self-reported autonomy ranking questions. In particular, we test whether the effect of disability on converting means into functioning together with people's freedom of choice decreases/increases their capability level. Thus, according to this specification, it means that the level of well-being, measured in terms of capability, is not only function of real achievements but rather potential fulfilment. In turn, this would suggest that the individual level of capability decreases as his/her freedom of choice on socio-environmental opportunities lower. We conduct this analysis at multi-dimensional level by investigating several aspects of human life. This pilot study indicates that disability, and in this particular case blind-

ness, has not always a negative impact in converting means into functionalities but that in some cases it is the lack of freedom of choice and opportunities that determinates the real level of individual well-being. Furthermore according to our findings we can state, as expected, that carrying out an analysis at the capability level reduces efficiency loss in local government's spending decision.

We should stress that, since we only carry out an empirical study with a reduced sample of individuals, we cannot make general conclusions for all types of disability. In particular, we cannot entirely eliminate the possibility that a low level of well-being results from impairments themselves. However, based on this experience we can state that the analysis of these particular cases needs to be integrated with household members' information because to the extent that low family member's freedom of choice and opportunities can reduce the overall collective well-being, household's deprivation would definitively affect well-being of people with disability. An aspect, however, that has not been investigated in our study due to the increased complexity it would add to the current study.

To complement this study we also developed a mathematical tool able to cope with the complexity and the vagueness of this concept. To this end we took advantage of the fuzzy set theory to introduce a Capability Index (CI), that has been designed to measure the overall level of deprivation among different dimensions. Finally, the use of different weight systems allowed us to characterize the way of aggregation different dimensions besides emphasizing the role of frequencies and individual ranking.

1.2. Research Objectives and structure

The aims of my PhD dissertation, titled "A Multidimensional Analytical Framework for Conceptualizing Disability and Well-being in the Capability Space" are twofold. First, it questions whether the standard models to disability are informative enough in assessing well-being of disabled people and, at the same time, whether a new conceptual model based on the Capability Approach (CA) allows to overcome most of the pitfalls associated to the previous modes. Second, it examines whether both the conceptual and empirical foundation of the existing works provides a comprehensive methodological and empirical prac-

tices of research to deal with a multidimensional understanding of well-being and human diversity. Thus, it discusses the relevance of incorporating a capability perspective in disability studies and provides a dynamic conceptualization of disability within a cross-sectional and a multidimensional analysis of well-being of people with disability, using data collected from a new dataset, the Blind-Disabled people Capability Survey (BCS). This study is of a theoretical and practical importance from both a conceptual and organizational points of view since it provides a more comprehensive set of information to measure well-being by referring to a phenomenological analysis of personal, environmental and social characteristics within a decision process that accounts for individual's freedom of choice and opportunities, besides transforming the tools into a valid and efficient informative device for social policies.

Therefore, this thesis attempts to address the limitations of unsuitable definitions of disability and inadequate measures of well-being, offering a new conceptual framework together with an analytical method.

The general objectives mentioned above have led to the development of a set of actions ranging from macro to micro level. Firstly, the model offered is a valid instrument, which can be implemented and replicated in other contexts. Secondly, the outcome of the analysis here proposed might be considered as a guideline for undertaking a series of efficient social policies at a local level. Indeed, it is shown that taking an action based on data that reveal people's actual rather than potential achievements may not be efficient in terms of social allocation of resources. This challenging point leads back to a central theme of discussion in various fields of human science, that is, the egalitarian distribution of opportunities among people. This issue becomes particularly controversial in the case of disability. Indeed, our argument is supported by the crucial debate on both the definition of disability and the appropriate approach for measuring well-being of disabled people. The debate involves considerations on the general framework to be adopted in analysing well-being of disabled person, as well as on the reasons and justifications of public policy intervention, which are mainly focused on the types of goods and services that should be provided to equalize opportunity. However, there is a crucial aspect that has long been neglected, which we aim to tackle in this work by

answering the following questions: how should disability be defined? Should equality of opportunities be our only concern? In which evaluative space should well-being be investigated? Do current methodologies cope with the freedom to choose to lead the kind of life that a person values most? Is this to be considered one of the fundamental aspects of human life? What do actual data available on disability tell us? Is this information enough to direct local public interventions efficiently?

In the light of what we consider to be the fundamental issues lacking in the current analysis, we attempt to provide a general framework by outlining the importance of some aspects, which need to be considered in assessing human well-being, especially in the case of disabled person. Moreover, this framework further develops the capability approach, as proposed by Amartya Sen, emphasizing the importance of measuring well-being in a broader, more inclusive space, that is, in capabilities. In agreement with the two main objectives, all these questions are addressed in this thesis in different chapters as follows: a general introduction of the work is presented in the first Chapter that includes a preface, some general information and a description of the structure of the thesis.

The second chapter offers an overview of different approaches to disability and underlines their limits. For long time disability has been seen just from a singular aspect either medical or social, which in turn implied the use of actions mainly addressed to medical care or reorganization of social environment. Nevertheless, recent concerns about its definition and measurement have raised a number of critics on both a theoretical and analytical level, which eventually have led to a reconsideration of the previous paradigms.

To this end, as far as we are concerned with the effect of physical/mental disability on people's lives, we consider of relevant importance to investigate it within a new conceptual framework where a central role in determining the interaction between individual, environmental and social characteristics is played by people's choices.

A further step is made by analysing disability as a cause or consequence of poverty. As the two aspects – disability and poverty – can be closely connected, it is essential to understand the role of local and national regulations in the context of disability. The whole description is a preliminary step crucial to the introduction of an alternative defi-

inition of disability, in which opportunity and freedom of choice have a major role beyond many other aspects.

The third chapter aims to include the definition of disability in an evaluation scheme of well-being for disabled people. It starts from a description of traditional welfare economics theories and of the main aspects related to well-being assessment. It then comes to the conclusion that, as various aspects of human life are missing in the mainstream theories, these theories are inadequate for measuring well-being and therefore for assessing well-being of people with disability. Thus, we base our research on an alternative approach to welfare economics: the Capability Approach (CA). This Approach was developed in the field of economics and has been marginally used to study disability but it places the definition within a wider spectrum of human development (Bakhshi et al., 2007). We do use this approach in agreement with what has been noted on the CA provision of additional insights into the study of disability since the CA looks not just at what a person actually is or does (functionings) but at the set of opportunities from which a person can choose (capabilities). Therefore, the core elements of the CA and the different concepts which relate it to human well-being will be illustrated. A distinction will also be made between well-being and agency as achievement and freedom. Finally, in this chapter, we will present two different conclusions: a specific conclusion which asserts that disability can be understood as a capability deprivation, and a second and more general conclusion which states that an evaluation of human well-being has to be made in the space of capabilities.

Chapter four goes back to the theoretical issues looking at practical problems. Supported by the idea that the CA, and in particular its capabilities space, offers a general informational base on which disability might be investigated, we have developed an instrument able to understand disability at three different levels: availability of goods/services, opportunity to access them and last, but not least, the freedom of choice that disabled people have in achieving the type of life they most value. Thus, in order to illustrate the different process through which this study has been undertaken we will proceed as follows: at the outset of the chapter a strong case is made for engaging primary data in operationalizing Sen's CA in assessing well-being of people with disability. The strength in setting primary data for assessing capabilities of people with disability is outlined together with the description of

advantages and disadvantages of using relevant secondary data. This description is supported by a schematic representation of our conceptual model applied to disability, which highlights not only the relevant elements that should be investigated in assessing human well-being, but also those interaction aspects that should be considered in a dynamic representation of human life. This discussion is followed by an explanation of the reasons why we need to build an appropriate tool to collect primary data especially when we deal with the relevance of opportunities and freedom of choice in assessing human well-being. Thereafter, the main methods for building a questionnaire are described. Lastly, in the final section of this chapter the introduction of a new questionnaire to assess the well-being of people with disability in the capability space will be presented. Chapter five deals with the methodological issues associated with both the operationalization of the CA and the assessment of a synthetic index of well-being. These tasks are accomplished through a number of steps functional to the explanation of the final results. First, we focus on the description of the sample characteristics paying particular attention to the sample size and its construction. This discussion is followed by a related description of the variables and dimensions selected in this study. In order to understand the adequacy of the structure of our questionnaire each dimension is broken down according to the set of specific variables.

Second, we present the mathematical tools that we have chosen to operationalize the CA, the Fuzzy set Theory, and examine the appropriateness of the theory to deal with vague and complex concepts such as those associated to the CA and disability. Further, we offer a general panorama of the conventional indicators to well-being besides highlighting the difference between absolute and relative form of deprivation.

The Chapter ends with the description of our Capability Index (CI) and all the aggregation phases related to it.

Finally, Chapter six presents an interpretation and discussion of the empirical application of the conceptual model and the instrument developed in the thesis. In order to highlight the relevance of individual's choice for efficient policy-maker decisions, we discuss how an assessment of well-being that does not take note of this aspect can lead to an inefficient public spending. This aspect is illustrated by analysing the difference between the two main evaluation spaces within the CA,

namely functioning and capability. In addition the analysis and results of the different dimensions are discussed. Finally, the results of this study on the current state of well-being of blind and partially sighted people are reported based on a decomposition of the CI by personal and social characteristics.