"To Make People Count, We Have to Count People Right": a Critical Analysis of the Existing Statistics on Persons With Disabilities

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Résumé

The issue of inclusion of persons with disabilities (PWD), in Italy and in the world, is urgent and more acute. Awareness of rights, and self-determination, has taken root, but it is not reflected in the implementation of adequate services, systems and policies. Experiences in this sense are sporadic and do not become a model; the absence of satisfactory and decisive interventions increases the risks of isolation and impoverishment, producing the "disappearance" of PWD. But how many people are we talking about? What personal traits can describe them? What are their failures and successes, their needs and wants? What life do they lead? When, why and how did some go off the social radar? How did it happen that others were successful? The Convention on the Rights of Persons with Disabilities (UN 2006) stresses the importance of reliable and disaggregated data, describing their living conditions. International organizations have addressed this task and gave rise to important initiatives, but recently, the Disability Data Portal demonstrates that the data relating to disability are unsatisfactory, confused, difficult to compare and highlights how these gaps unveil inequality and the ineffectiveness of policies. Similar criticism also applies to Italy (ISTAT 2021). The impossibility of systematically collecting the characteristics of persons, contexts and projects, nullifies the opportunity of correlating them, leading to the abandonment of the development of a self-determined life project, which is adapted based on existing services. To overcome these issues the University of Bergamo promoted the project "More than just numbers: Disability data matter" aiming at elaborating a common methodological theoretical model, which will be sufficiently innovative and shared to implement an exhaustive collection of data concerning both the lives of PWD (3-64 years old) and the contexts connected to them, according to the model of rights for the individual and for the ecosystem. The first of the seven phases of the project is a critical analysis of the existing statistical, demographic and administrative data on disability, at international and Italian levels. This phase aims to answer the following research question: at international and national level, how are statistical and demographic data on disability collected, organised and analysed by the different agencies?

This contribution presents the results of this phase. Through a web search of 14 nations and 6 supranational (WHO, UNICEF, ILO) and European organizations (Eurostat) websites, 7 statistical documents, 113 international and 13 Italian surveys were found. The study of this material made it possible to extrapolate and organize, in a specific reading form, information related to theoretical and methodological plan of the surveys. The results reveal, both at an international and national level, a strong heterogeneity with particular reference to: a) the adopted models of disability (the medical one still appears to be the one predominantly

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used); b) the questions used that can sometimes be the same suggested by international documents (WG 2002) and sometimes self-produced by the national statistics offices; c) the life context explored (especially education and work); d) the methodological way with which the collected answers are processed to discriminate between respondents with and without disabilities, making it difficult a comparison of the data.

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