
Norms as produced by "institutions" and "community-based services" within a human rights framework: reflections and challenges to rethink (des)institutionalization and community living policies

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Abstract

As a student developing PhD research (SFRH/BD/144069/2019), I immersed myself in the debate between institutionalization, deinstitutionalization and community living in intellectual disability, through literature reviews and theoretical constructions influenced by critical disability studies and human rights approaches. Portuguese studies and debates on this topic are scarce, despite the planning and implementation of policies aimed at promoting independent living and deinstitutionalization. Portugal, like other countries in Southern Europe, presents specificities, namely the predominance of care in a family context. The services for the accommodation of people with intellectual disability consists predominantly of residential homes and autonomous residence. By size and configurations, the first response can be considered more institutionalizing, and the second more community-based, human rights oriented. This presentation seeks to contribute to analyzing the place and expressions of human rights in the norms produced by each residential home or autonomous residence, identifying, and problematizing the "essence" of the administrative typologies. More precisely, I propose a presentation focused on the following aspects: i) trajectory of policies and residential services for people with intellectual disabilities in Portugal, identifying and reflecting on their objectives, trends, assumptions and rationalities; ii) analysis of the operating norms written by institutions and community-based services, through the framework of human rights (principles and articles); iii) analysis of the similarities and differences found between typologies and internally, reflecting on other possibilities of categorization from the results; iv) reflections and implications of the results in terms of policies and research in this area. This research is based on a set of data, such as books in this area, documentation, and articles, mainly to understand the social conditions that led to the construction of institutions for people with intellectual disabilities, their continuity and questioning. To analyze the norms produced by the institutions we identified the various institutions and community-based services existing in Portugal and consulted their websites to collect internal regulations. The analysis of these documents is carried out using content analysis, by adapting human rights principles and articles, frequency analysis, and multivariate analysis to try to identify profiles. The results will be presented at the conference, deepening for

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example: the "ambiguity" of the concept of institution and community-based services, reinforced by the introduction of the concept of "non-institutionalization"; the main arguments / rationales for the construction and continuity of responses of institutional nature; the diversity and similarities found in terms of human rights in the operating rules of the residential homes (institutions) and autonomous residence (community-based services). Although the texts analyzed have specific purposes, I argue that the human rights framework is relevant to analyze and understand the institutionalizing nature that govern lives in community-based services and institutions going beyond administrative typologies and enabling their discussion. This is an important challenge for the development of deinstitutionalization and community living policies.