

CFP – 11th Annual Conference
ALTER – European Society for Disability Research
EHES – Centre des colloques, Campus Condorcet Aubervilliers, Paris, France
June 29 and 30, 2023

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Title:

Self-determination in residential services for adult with intellectual disability. Analysing staff members' perceptions and practices using semi-structured focus group discussions

Abstract

Art. 19 of the UN *Convention on the Rights of Persons with Disabilities* (2006), reinforced in *General Comment n. 5* (UN 2017), promote/ensure equal opportunities to all persons with disabilities (PwD) to choose how, where and with whom to live, not limited to the place of residence but including all aspects of person's living arrangements. This legal mandate went along the dissolving of "traditional" (or large) residential institutions for PwD and the establishment of community-based living support measures. In particular, this replacement was frequently advocated on the basis that such latter services are likely to facilitate choice and self-determination (SD) (Clement&Bigby 2010). According to the literature the great value of this revolution continues to collide with three main shortcomings (Kozma, Mansell&Beadle-Brown 2009; Robertson et al. 2001). Firstly, opportunities for SD are highly limited for many individuals with intellectual disabilities (ID) within different residential settings. Secondly, although there is considerable evidence to suggest that people in smaller community-based residential settings may have more choice opportunity than people in larger ones, such decisions do not concern «how, where and with whom to live» nor the choice of support personnel. Finally, four factors have been associated with increased levels of SD: capacity building; small size of the house; being supported in independent living arrangements; at staffing level, greater opportunities for self-determination are associated with lower levels of support.

This article presents evidence from the exploratory phase of a three-years research-intervention project (2019-2022) aiming at developing an individualized and integrated co-designing model to guide residential services and personnel to support/promote SD in adults/elderly persons with ID. Drawing on the Systemic Approach (Giraldo 2020) and methodologically on the Grounded Theory model (Charmaz 2000), the perspective of 16 staff members from several residential services in Bergamo area (Italy) were collected using semi-structured focus group discussion techniques (Morgan 1997) in order to highlight ideas/opinions/perceptions about the construct of SD (particularly related to ID) and practices/strategies/experiences to support it within their services. Two major findings emerged opening up the discussion on today/future's challenges: a) even though personnel might have come across the concept of SD, they might not have obtained the full comprehension of its component and the strategies to promote it in residents' daily life activities and living arrangements; b) the overall persistence of standard solutions based on service organizational/management concerns and not on the real needs, desires and aspirations of the PwD.

References

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