

Book Review

Callus, A. (2013). *Becoming self-advocates: People with intellectual disability seeking a voice*. Bern, Switzerland: Peter Lang.

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Dr. Anne-Marie Callus is a faculty member at the University of Malta. Her research interests include disability studies and self-advocacy for people with disabilities. She was formerly the executive director of the National Commission Persons with Disability.

Dr. Callus introduces the concept of disability and analyzes how the label of “intellectual disability” is socially constructed. She discusses the social model of disability, which distinguishes the bodily impairment from the degree to which that impairment excludes one from social life. She contrasts this with the individual model, which views disability as an intrinsic part of a person who is unable to adapt to the environment, and it is consistent with the medical and charity models. The individual model explains that society provides services to people with disabilities either as an attempt to rehabilitate them or out of kindness. The social model, on the other hand, means that services must be provided within the context of the environments in which people live on a daily basis and must challenge the barriers that exist within those environments.

The author discusses her research from her involvement with the Kummissjoni Nazzjonali Persuni b'Dizabilita, translated as National Commission Persons with Disability, and its Consultative Committee (KCC), which was made up of a dozen people with intellectual disabilities. She used a qualitative methodology of participant

observation, structured and semi-structured interviews, minutes of monthly meetings over a period of two years, as well as analysis of various documents. She adopts a social constructionist view, which recognizes the role of language, labeling, and identity in the subjective experience of reality. She provides a context by presenting an historical view of intellectual disability from the 1940s to the present and the development of the self-advocacy movement, beginning in Sweden, within the United States and the UK, and more specifically, in Malta.

Dr. Callus discusses the experience of offering a course to individuals with intellectual disabilities to teach self-advocacy and public speaking skills, and the resistance she witnessed from some in the disability community. She continually faced a “gatekeeping” issue in the process of inviting and engaging members. Gatekeepers were parents, caregivers, and service providers who exerted control over the information given to consumers in an effort to protect them and that simultaneously disempowered them.

The KCC members are introduced, and many excerpts of conversations and interviews are included to demonstrate the restrictions placed on their lives through the structures of society and well-meaning caregivers. She describes the process they went through as they developed self-advocacy skills. The concept of help is explained in terms of the dynamic that can sometimes

increase dependency when it could, instead, be used as a way to facilitate autonomy, self-determination, and interdependence.

The concept of labeling is discussed at length, and the label of “intellectually disabled” is at first rejected by the persons who try to distance themselves from the negativity and stigma of it. Yet, ironically, it is this rejection of the label that is also an obstacle to their development as self-advocates. To be strong self-advocates, they came to reclaim the label in a new way, imbued with the meaning they, themselves, gave to it. They came to develop a new identity, with impairment viewed as a positive attribute.

I found the frequent use of the term “disabled persons” to be distracting and in contrast to my own preference to use person-first language. Interestingly, there is also a discussion within the

KCC committee meeting of the use of language, in which group members are asked to express their agreement or disagreement with various terms. The group disagreed with the term “disabled,” and there was not a clear consensus about the term “person with disability;” however, the group approved of the term “person with intellectual disability.” Regardless of word choice, the author’s passion for empowering this population and helping them to participate more fully in every aspect of their lives is quite evident.

Readers in other countries may have already experienced some of the things discussed in this book, especially those who work within consumer-driven agencies. The author tells the story of how self-advocacy developed in a specific setting within a particular cultural context (Malta). I would recommend this book to anyone who might be able to apply the lessons learned to their own settings.