

Ashtavakra Institute of Rehabilitation Sciences & Research

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Topic- Self Advocacy for Adults with Disabilities

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Name of the Journal (APA)- Kennedy, Killius, Bonnie, Campione, J. C. (1986) 30(9), 911–920.

ABSTRACT

Objective: The goal of self-advocacy is to equip people with knowledge to make informed, authentic decisions, and to empower them to make those decisions.

Methods: In this qualitative study the authors used a constructivist grounded theory methodology. We wanted to focus on the significance of self-advocates' experiences and the possible impact of being a self-advocate on their social participation. We used emancipatory principles as well, "where the views of people with disabilities are central to the research process and the value of the research undertaken is gauged by how far the process of participation makes a contribution to the individual or collective empowerment of disabled people.

The method used for data collection was focus group interviews. They were relaxed and informal, took place in the offices of self-advocates' groups. The questions concerned topics such as roles and tasks in adult life, meaning given to self-advocacy, personal experiences connected with self-advocacy movement, social participation.

The three focus groups, which were from the same organization in northern Poland, consisted of five to seven participants. All the participants are adults with disabilities who are active members of self-advocates groups. Potential participants were identified on the basis of interest in being interviewed.

The aims of the study were outlined during the introductory meeting. A total of eighteen participants, seven women and eleven men, ranging in age from 22 to 58 years decided to take part in focus groups. Participants were divided into three mixed groups. Every focus group interview lasted approximately one hour. Two major theme areas emerged from the data: meaning of self-advocacy and experiences of adults as far as social contacts and social participation are concerned. Names of participants and the service they are involved in have been changed due to confidentiality and anonymity.

Results: Equipped with a deeper understanding of the aspects of self-advocacy for adults with developmental disabilities, DSPs may more clearly identify the impacts of self-advocacy on adults with DD, their supports, and communities. Examples of such impacts include enhanced leadership skills and self-transformation (self-perspective) for adults with DD (Caldwell, 2010). It is "a structural change in the way we see ourselves and our relationships" (Mezirow, 1978: 100). Perspective, perception and self-perspective are entwined and malleable. As well, research suggests that self-advocacy for adults with developmental disabilities impacts, not only adults with developmental disabilities, but their families and support staff (Caldwell, 2010). Ultimately, self-advocacy for adults with developmental disabilities impacts communities, including the academic community, boards or advisory bodies and the communities they represent, and local communities through projects and initiatives.

Conclusion: Identity development, self-advocacy, and community connection are fundamental to the experience of having a disability. The process of disability identity development is strengthened and enriched through connection with others who have shared experiences, goals, and histories. This sense of disability as a political community can provide an important way to navigate ableism, stigma, and discrimination that youth with disabilities face daily. Understanding ourselves as connected to one another in this way strengthens the broader disability community and its goals as a whole.

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Keywords: intellectual disability; self advocacy; toolkit

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