



Impact Factor: 0.738 | Ranking: Education, Special 23 out of 39 | Rehabilitation (SSCI) 49 out of 71

Source: 2016 Rele:
Reports, Source:

Research and Practice for Persons with Severe Disabilities

rps.sagepub.com

Published online before print April 8, 2016, doi: 10.1177/1540796916637050
Research and Practice for Persons with Severe Disabilities June 2016 vol. 41 no. 2
116-131

Understanding Deinstitutionalization What Families Value and Desire in the Transition to Community Living

Jennifer L. Jones¹

Kami L. Gallus¹

¹Oklahoma State University, Stillwater, USA

Jennifer L. Jones, Department of Human Development and Family Science, Oklahoma State University, 233 Human Sciences, Stillwater, OK 74078-6122, USA. Email: jennifer.jones@okstate.edu

Abstract

The deinstitutionalization movement that began 50 years ago remains a current issue for professionals and families. Using qualitative phenomenology methodology, we investigated the experience of mandated deinstitutionalization for parents and siblings whose relatives with intellectual and developmental disabilities (IDD) transitioned from institutionalization to community living within the past 1 to 3 years. Findings from the current study align with previous research wherein, over time, most families shift from opposition to satisfaction regarding community living; however, family members' narratives in the current study reveal there is more to the process of deinstitutionalization than the outcome of satisfaction. Family members, regardless of current opposition or satisfaction, shared six common themes concerning what they desired and valued throughout the deinstitutionalization process: (a) respect our relative's history, (b) collaborate: make us feel like we are a part of the process, (c) provide quality care, (d) provide consistent care, (e) include my relative in the community, and (f) remember we are family. As the desirable goals of full community inclusion (e.g., education, community living, competitive employment) are implemented through policy and practice, professionals must continue to develop intentional collaborations with, and supports for, families during times of transition in conjunction with services and supports developed for individuals with IDD.

[deinstitutionalization](#) [community living](#) [intellectual and developmental disabilities](#)
[family system](#) [transition](#)

Received November 17, 2015.

Accepted January 29, 2016.