

Putting Research to Work for Military Families



Focus:
Civilian

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

Jones, J. L., & Gallus, K. L. (2016). Understanding deinstitutionalization: What families value and desire in the transition to community living. *Research and Practice for Persons with Severe Disabilities*, 41 (2), 116-131.
doi:10.1177/1540796916637050

SUMMARY: Professionals and families experiencing the transition from institutionalization to community-living often face additional stress and challenges. This study explored family members of individuals with intellectual and developmental disabilities (IDD) experiences regarding this mandated transition. Findings revealed six common themes reflecting a desire to connect and engage with communities and professionals of IDD services and support, but that they experienced barriers to doing so.

KEY FINDINGS:

- Family members' were respectful of their relatives with IDD as their experiences living in residential support institutions were places that they felt at home and had built meaningful relationships.
- There was a strong desire to collaborate among family members and agencies such as Developmental Disabilities Services, especially during the move and transition into the community.
- Acquiring, training, and retaining qualified staff who served their relatives in community-living were indicated as significant sources of stress for all family members.

IMPLICATIONS FOR MILITARY PROFESSIONALS:

Military professionals could:

- Partner with military families to help emphasize the importance of collaboration with the community throughout the deinstitutionalization process
- Provide ongoing support to military families as they adapt to community-living and new agency providers

IMPLICATIONS FOR PROGRAMS:

Programs could:

- Develop workshops for Service members and their families with IDD to provide them with effective strategies to communicate their concerns with community-living care
- Create curricula for the purpose of building systems of support and collaboration among individuals with IDD, their families, and community-living service providers

IMPLICATIONS FOR POLICIES:

Policies could:

- Continue to provide resources to support individuals with IDD and their families, especially during times of deinstitutionalization transition
- Encourage professionals who work with individuals with IDD and their families to promote collaboration among services to create a smoother transition and sense of community belonging

This product is the result of a partnership funded by the Department of Defense between the Office of Military Community and Family Policy and the USDA's National Institute of Food and Agriculture through a grant/cooperative agreement with The University of Minnesota.



Putting Research to Work for Military Families



METHODS

- Participants were recruited through mailed invitation using contact information provided by Oklahoma Developmental Disabilities Services of clients with IDD who transitioned out of institutions.
- Semi-structured interviews (45 to 120 minutes in length) were conducted with family members of individuals with IDD, including questions about family history, relationships, roles, communication, and decision-making regarding institutionalization and deinstitutionalization.
- Interview content was coded and six common themes were identified in family members' responses.

PARTICIPANTS

- The sample included 23 family members, 10 were mothers, six sisters, three fathers, three brothers, and one was a brother-in-law all of which were relatives of 12 males and seven females with IDD.
- Ages ranged from 51 to 85 years ($M = 65.33$, $SD = 9.01$) for family members and 35 to 70 years ($M = 52.31$, $SD = 10.03$) for individuals with IDD.
- A majority of the family members were White ($n = 18$), followed by two Black, and one Latino. No data were provided on the race or ethnicity of two family members or individuals with IDD.

LIMITATIONS

- All of the sample were relatives of individuals with IDD who had experienced mandated deinstitutionalization, so results may not extend to those who had not experienced this transition.
- Participants were recruited from Oklahoma Developmental Disabilities Services, thus limiting the ability to generalize the results to families of relatives with IDD residing in other states.
- The study was cross-sectional therefore no claims can be made based on what factors caused outcomes of community-living among family members of relatives with IDD.

AVENUES FOR FUTURE RESEARCH

Future research could:

- Investigate whether there are differences or similarities in opinions and experiences regarding care and level of support among community-living staff and relatives of individuals' with IDD
- Explore the long-term experiences of community-living for family members of relatives with IDD, including family roles, relationships, and responsibilities
- Examine the deinstitutionalization experiences of family members and staff of individuals with IDD in other states or communities, such as schools

ASSESSING RESEARCH THAT WORKS



For more information about the Assessing Research that Works rating scale visit:
<https://reachmilitaryfamilies.umn.edu/content/assessing-research-that-works>