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May 12, 2016

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Family Members Shift from Opposition to Satisfaction Regarding the Deinstitutionalization Process

New study shows that family members of people with disabilities report initial opposition and then growing satisfaction with the transition from institutions to community living

WASHINGTON, DC – This week, TASH’s peer-reviewed research journal, Research and Practice for Persons with Severe Disabilities (RPSD), released a new study on deinstitutionalization. Results show that the majority of family members interviewed not only reported initial opposition to deinstitutionalization, but also reported growing satisfaction with community living in the short-term transition.

“This study offers a candid view of families’ experiences with deinstitutionalization and the factors that helped change their beliefs about the value of community living,” said Stacy Dymond, editor of RPSD. “Factors identified within the study offer important insights regarding the types of supports needed by individuals with severe disabilities and their families during the transition to integrated settings.”

Families witnessed growth and development after their relatives moved to the community. “Since she’s been out, there has been a change in her,” said Rachel, sister of a 66-year-old female. “She is very verbal.” Families also expressed feelings of remorse. “The only disappointment I have would be that we hadn’t done this a lot sooner,” said Keith, brother-in-law of a 64-year-old male.

The purpose of the study was to discover and describe family members’ experiences with the deinstitutionalization process and to identify salient factors influencing their perspectives of the transition to community living for their son, daughter, or sibling leaving a state-run institution. The authors conducted 19 interviews with 23 family members. Regardless of current opposition or satisfaction, family members shared six common themes concerning what they desired and valued throughout the deinstitutionalization process: (a) respect for our relative’s history, (b) collaborate: make us feel like we are 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.

Although the majority of family members interviewed in this study report satisfaction,
the narratives highlight deinstitutionalization as an ongoing and evolving process that requires intentional collaborations with, and supports for, family members.

This study can be found in TASH’s member journal, Research and Practice for Persons with Severe Disabilities (RPSD), Volume 41 Issue 2. The article will be made available to the public until June 12, 2016. Thereafter, it will be available to only TASH members with professional, associate, student, and organizational memberships. To learn about TASH membership, visit www.tash.org/join.

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A 501(c)(3) non-profit organization, TASH is an international grassroots leader in advancing inclusive communities through research, education and advocacy. Founded in 1975, we are a volunteer-driven organization that advocates for human rights and inclusion for people with the most significant disabilities and support needs – those most vulnerable to segregation, abuse, neglect and institutionalization. The inclusive practices we validate through research have been shown to improve outcomes for all people. More information about TASH can be found at www.tash.org.