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Groundbreaking Survey of Families of Adults with Developmental Disabilities Dispels Myths, Shows Institutional Homes Are Part of Our Communities

VOR, a national nonprofit organization that advocates for individuals with intellectual and developmental disabilities, including autism, has released the results of its survey of families of individuals with profound disabilities.

Believed to be the first of its kind, the “Giving a Voice to Families and Guardians” survey gathered the perspectives of families of individuals with profound disabilities who receive care in Medicaid Intermediate Care Facilities (ICFs) or in home and community-based settings. About three-quarters of respondents for both settings were parents and guardians.

“There is the assumption that all people with disabilities are better served in small settings, an assumption supported by other surveys,” said Jill Barker, a VOR Officer and Board Member who chairs the committee who undertook the survey. “Yet, the opinions of the families who know best are rarely sought.”

The 1999 U.S. Supreme Court’s *Olmstead* decision ushered in a new decade of aggressive “deinstitutionalization,” the movement of individuals with developmental disabilities from facility-based settings to smaller homes. This trend continues in states, with pressure from the federal government.

Olmstead, however, does not mandate deinstitutionalization, says VOR.

“*Olmstead* should have settled the institution versus community debate,” said Tamie Hopp, VOR’s Director of Government Relations & Advocacy. “It expressly supports the right of individuals to receive care according to individual choice and need.”

The survey, VOR says, was an opportunity for families and guardians to have their perspectives registered.

Contrary to current public policy and trends, which support serving all people with disabilities in small homes regardless of level of disability, respondents’ for individuals receiving facility-based care indicated a high level of satisfaction with their individuals’ ICF and facility-based homes, staff competency, access to health care and services, and community integration.

“These responses revealed a sharp contrast between common misperceptions of ‘institutions’ as segregating and isolating environments and the perceptions of the families and guardians of individuals living in these settings,” remarked Barker. “A strong majority believed that their individual would do poorly in a small, unspecialized setting.”

VOR also asked respondents what they would like the government to know about deinstitutionalization, with most responding that what mattered most to them was that their family members received the care they needed and that their right to individual choice was respected.

For information on how to receive a copy of the complete survey report, please contact VOR at info@vor.net.

About VOR: VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. Standing up for long-term care facilities and community disability programs, VOR is dedicated to maintaining individual family choice for people with intellectual and developmental disabilities. For more information about VOR, including information about our programs and a press kit, please visit <http://vor.net/about-vor>.