



Exploring Progress Since the *Olmstead* Decision: Results from the ADA PARC Interviews with People with Disabilities Transitioning from Institutional to Community Living

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The ADA Participatory Action Research Consortium

The Americans with Disability Act (ADA) Participatory Action Research Consortium (ADA-PARC) is a collaborative research project between ADA Regional Centers, university-based investigators, disability-related community organizations such as Centers for Independent Living (CILs), and other stakeholders.

The purpose of ADA-PARC is:

- To look at participation disparities experienced by people with disabilities post ADA & *Olmstead*
- To identify & examine key environmental factors contributing to these disparities
- To benchmark participation disparities and highlight promising practices at state & city levels
- To action-plan strategies for dissemination and utilization of findings to be used by ADA Centers and others in community capacity building & systems change initiatives

Olmstead Interview Project

The 1999 *Olmstead v L.C.* Supreme Court decision is considered one of the most influential applications of the ADA, affirming the role of this legislation to mandate full community integration of people with disabilities, including the support of ongoing deinstitutionalization efforts.

One phase of the ADA PARC project included conducting over 150 interviews nationwide of people with disabilities who have transitioned from institutional to community living in order to:

- Compare experiences between institutional and community-based settings within domains of: living situation, choice/control, access to care, and community integration and inclusion
- Quantify current community experiences of: life satisfaction, transportation access, social interactions, financial security, disability identity, advocacy engagement, and access to services
- Obtain qualitative data related to the meaning ascribed to transitions, community participation, and the personal impact of the ADA

The interviews include a combination of: (1) the **Money Follows the Person (MFP) Quality of Life** inventory questions (2) the **NOD/Harris Survey of Americans with Disabilities** questions (3) open-ended questions

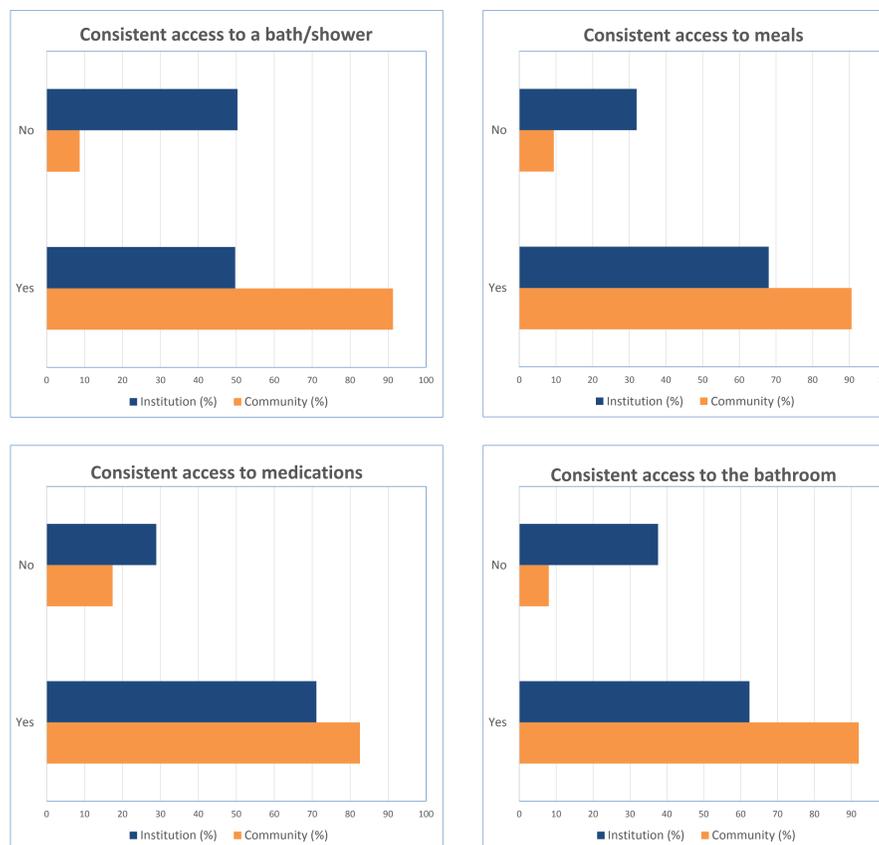
Inclusion Criteria

- Identifies as having a **disability**
- Was **institutionalized** in a setting such as a nursing home, state-operated psychiatric or developmental facility, institute for mental disease (IMD), intermediate care facility (ICF), or large group home
- Has **transitioned out** of an institution into community living within the **last 5 years**
- Was **age 18-64** at the time of transition
- Is able to communicate with accommodations as needed

Participant Demographics (n=153)

- **Gender:** Women (50.3%); Men (49.7%)
- **Age (in years):** 18-29 (5.9%); 30-44 (18.3%); 45-64 (73.8%); 65+ (2.0)
- **Race:** White (51.6%), Black (45.1%), American Indian/Alaska Native (5.2%); Latinx (4.6%); Asian (2.0%)
- **Disability Category:** Physical (74.5%); Psychiatric (49%); Chronic Health Condition (37.9%); Blind (13.1%); Cognitive (11.8%); Speech (9.8%); Deaf (6.5%); Intellectual (4.6%); Autism (1.3%)
- **Time in institution:** 1 mos. to 26 yrs. (M= 3.75 yrs.)
- **Time in community:** 1 mos. to 5 yrs. (M= 18 mos.)
- **Employment:** Unemployed (82.3%); Retired (7.2%); Employed (5.9%)
- **Marital Status:** Never married (47.7%); Divorced/Separated (33.3%); Married/Civil Union/Living with Partner (11.8%)
- **School:** <HS (15%); HS grad/GED (34%); Some college (36.6%); College grad (14.4%)
- **Income:** < \$15K (85.5%); \$15-25K (6.5%); \$25K-35K (3.9%)
- **Primary source of income:** SSI/SSDI (92.2%); Retirement (3.3%)

Focus On Access To Care



Participants Said...

On care in the institution:

- "In the facility, I had to beg for treatment"
- "There was a 30-minute window, and they'd throw the meal away if you missed it. Or it would be cold."
- "The facility was substandard and often did not order my meds in time"

On care in the community:

- "It's been tough finding reliable caregivers, especially now, since caregivers can't work over 40 hours a week and the cuts to Medicaid are making it more difficult to stay in the community."
- "[I want to] get on the bus, train, do my business, and go shopping. [I would need] a motorized wheelchair, transportation, help with carrying things. The community is not accessible without a motorized chair"
- "Outside life is not perfect but its autonomous"

Institution vs Community:

"You lay down and dream about the day you will leave the nursing home. It is as bad as going to prison. Out in the community I feel like maybe there is still hope for me. I feel like I am gaining my life back"

Supporting Community Living

Respondents in this study were **14x more likely to like where they lived** and **2x more likely to feel safe living in the community** versus an institution. Unfortunately, disability advocates report that many people are **not aware of their rights** related to deinstitutionalization. When there are resources available to people with disabilities in the community, many **do not know how to access** them.

In response to this community need, Chicago's CIL, Access Living provides the *Stepping Stones* program, which pairs mentors with disabilities who have successfully transitioned to community living with people who are still living in institutions or have recently moved out. This program provides much needed **peer support, knowledge about rights, and resource referrals.**

Conclusions and Recommendations

People with disabilities in this study report overall **increased satisfaction, feelings of safety, and better access to care in the community** compared to institutional settings. This contradicts often-used justifications for people with disabilities to be institutionalized. Despite these improvements after transitioning to the community, individuals **continue to face barriers** to accessing needed services that impact participation, often related to **economic and transportation issues.**

Providing care in the community context has **considerable economic benefit** for state budgets, and **outstanding personal benefits** for people with disabilities. Therefore, it is in the best interest of policy makers and clinicians to continue to support individuals and the disability community as they work to transition from institutions to community living, and provide comprehensive supports to help them thrive.

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