



Institute on Disability and Human Development

ACCESSIBLE RESEARCH SUMMARY

An Analysis of Movement from Illinois State-Operated Developmental Centers From July 1, 2016-December 31, 2018

People with intellectual and developmental disabilities (IDD) have historically lived in large residential settings like state-operated developmental centers (SODC) and skilled nursing facilities (SLNs). The movement of deinstitutionalization, or transitioning people out of large congregate facilities into smaller community settings, has gained traction and community living is generally considered as the model of habilitation for people with IDD.

The Institute on Disability and Human Development, University of Illinois at Chicago, examined transitions out of SODCs from July 1, 2016 to December 31, 2018 to determine characteristics of and outcomes for persons transitioning out of SODCs in Illinois. This project is a continuation of previous studies, that started in 2001, for the purpose of finding trends related to depopulation of SODCs in Illinois.

Findings from July 1, 2016 through December 31, 2018

How many people moved out of Illinois SODCs?

- 200 people moved: 193 people moved once and 7 people moved twice.
- 41 persons died.

What are the characteristics of those who moved out of SODCs?

- Average age 46.8 years and 76.5% were male.
- 52.0% had family members as their guardians, 24% had a State guardian.
- Average length of living at SODC was 12.7 years.
- 65.0% people who transitioned were white.
- 58.0% had at least one psychiatric diagnosis. The most frequent psychiatric diagnoses were mood disorders (27.5%) and psychotic disorders (21.0%).
- 33.5% had a profound disability.
- Average Inventory for Client and Agency Planning (ICAP) Service Level score of 53.6, which indicates regular personal care service need.

What type of residential setting did individuals move into?

- Most moved to either CILAs (31.4%) or SNFs (26.6%).
- 9.2% went to jail, 8.2% went to another SODC.
- 7.7% went to an ICF/DD, 6.3% went to a family home.
- 6.3% went to an "other" setting, 4.3% went to a mental health center.

What extent did individuals remain in their post-transition setting?

- Nearly half (47.8%) are still in their first setting, 21.7% returned to an SODC, and 16.4% have died.
- Of the 64 transitions that went to a CILA and who had a current status, nearly three-quarters remained in the same setting and with the same service provider.

How do the demographics and characteristics of persons who transitioned compare across residential settings?

- Those transitioning to community settings (CILA and family), were generally younger (CILA: 41.1 mean age, family: 32.0 mean age).
- People in community settings (CILA and family home) had lower health risks, especially compared to those in institutional settings like ICF/DDs, SNFs, and SODCs.
- People who had been in SODCs the longest generally transferred to institutional settings including ICF/DDs (M=24.6 years) and SNFs (M=24.7 years).

Why did people return to a SODC and did they receive technical assistance?

- Most (41.0%) returned for behavioral reasons, followed by needs for short-term therapy (27%), other (24%), and medical (5%); 3% did not have a reason.
- The majority received technical assistance.

What are the characteristics of people who died since transitioning from a SODC?

- 63 people died at a SODC (41) or after they transitioned out of a SODC (22 people). Individuals who died in an “other” setting were the highest health risk and had the lowest IQ.

Conclusion

Two themes surfaced from the study: (1) Changing demographics and characteristics of the people transitioning and (2) Challenges in community settings for people with ID and a psychiatric diagnosis. The changing characteristics over the three years include: increased transition into CILAs; and more persons who were non-white, younger, and having lower personal care service need and lower health risks. The age of those who remained in CILAs after transition decreased.

The data supports the need for policies and programs, including continuing initiatives such as the Short-Term Stabilization Homes and Support Service Teams, to address people with intellectual disabilities and a psychiatric diagnosis in non-institutional settings. Additional research should be completed to better understand ways to increase community capacity to address transitions from Illinois' SODCs.

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