

ACCESSIBLE RESEARCH SUMMARY

An Analysis of Movement from Illinois

State-Operated Developmental Centers: Transitions between

July 1, 2016-June 30, 2020

People with intellectual and developmental disabilities (IDD) have historically lived in large residential settings like state-operated developmental centers (SODCs) 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 for people with IDD.

The Institute on Disability and Human Development, University of Illinois Chicago, examined transitions out of SODCs from July 1, 2016 to June 30, 2020 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.

How many people moved out of Illinois SODCs?

- 342 people moved, 15 moved twice and 1 moved three times.
- Another 127 persons died within SODCs or in their discharge setting.

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

- Average age was 44 years and 75% were male.
- 49% had family members as their guardians, 28% had a public guardian.
- Average length of living at SODC was about 12 years.
- Two in three people who transitioned were white.
- Almost two in three people had at least one mental illness diagnosis. The most frequent mental illness diagnoses were mood disorders (30%) and psychotic disorders (21.0%).
- Over one third had a mild intellectual disability.
- Average Inventory for Client and Agency Planning (ICAP) Service Level score of 54.8, which indicates regular personal care service need.

What type of residential setting did individuals move into?

- Less than one third moved to CILAs or I-CILA.
- 23% moved to skilled nursing facilities, 11% went to another SODC.
- 9% went to jail, 6% went to an ICF/DD.
- 9% went to a family home.
- 6% went to an "other" setting, 5% went to a mental health center.

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

- Nearly 45% are still in their first setting, 22% returned to a SODC, and 14% died.
- Of the 107 transitions that went to a CILA and who had a current status, over two-thirds 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 mean age, family: 34.8 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 transitioning to ICF/DDs and SNFs had the highest health risks, lowest average ICAP Service Level scores (indicating more support needed), and the lowest average IQs.
- People who had been in SODCs the longest generally transferred to institutional settings including ICF/DDs and SNFs.

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

- Most (38%) returned for behavioral reasons, followed by needs for short-term therapy (25%), other (23%), and medical (15%).
- The majority received technical assistance.

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

- 82 people died at a SODC and 45 died after they transitioned out of a SODC.
- Individuals who died in an “other” setting had a slightly higher health risk and lower IQ than those who died in SODCs.

Conclusion

Two themes surfaced from the study: (1) Changing demographics and characteristics of the people transitioning and (2) Increasing challenges in community settings with an increased number of people with ID and a mental illness diagnosis. The changing characteristics over the four years included: increased transition into CILAs from FY17-FY19, and family in FY20; and more persons who were non-white, younger, and having lower personal care service needs and lower health risks. The age of those who remained in CILAs after transition decreased.

The themes suggest the lack of capacity in the community to be able to receive additional transitions, especially from people with mental illness diagnoses. The finding also supports the need for policies and programs including continuing initiatives to address people with intellectual disabilities and a mental illness diagnosis in non-institutional settings. Additional research should be completed to better understand ways to increase community capacity to address transitions from Illinois' SODCs.