

ACCESSIBLE RESEARCH SUMMARY

Research Brief: An Analysis of Movement from Illinois State-Operated Developmental Centers: Transitions between July 1, 2020-June 30, 2021

Many people with intellectual and developmental disabilities (IDD) lived in large group settings. These settings usually have a lot of people with IDD. Some people with IDD still live in these large group settings. In Illinois, they are state-operated developmental centers (SODCs). More people with IDD are moving out of these large group settings and into the community. This movement from large group settings to the community is deinstitutionalization. Many people think the community is the best place for people with IDD to live.

The Institute on Disability and Human Development, University of Illinois Chicago, looked at transitions out of SODCs from **July 1, 2020 to June 30, 2021**. The purpose of looking at transitions was to see what kind of people with IDD moved out of SODCs. We also wanted to see how people did after they moved out of SODCs. We have looked at transitions out of SODCs since 2001. Having data since 2001 has helped to identify trends in transitions out of SODCs. All data reported are as of March 2022.

How many people moved out of SODCs?

- 82 people moved, two people moved twice.
- Four out of five moves were out of Shapiro, Choate, and Kiley SODCs.

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

- The average age was 47 years and 73% were male.
- One in two people had family members as their guardians, 28% had a public guardian. 17% of people were their own guardian.
- The average time people lived at a SODC was about 14.5 years.
- Two in three people were white.
- More than two in three people had at least one mental health diagnosis. The most common mental health diagnoses were mood disorders (33%), psychotic disorders (15%), and anxiety disorders (15%).
- Almost one third had a mild intellectual disability.
- The average Inventory for Client and Agency Planning (ICAP) Service Level score was 54.4. This ICAP score means most people have regular personal care needs.

Where did people move to?

- One in four people moved to CILAs or community integrated living arrangements.
- 26% moved to skilled nursing facilities (SNFs). 6% went to another SODC. 6% went to an intermediate care facility for developmental disabilities (ICF/DDs).
- 9% went to jail. 2% went to a state-operated mental health center (MHC). 18% went to a family home. 7% went to an "other" setting.

To what extent did individuals remain in their post-transition setting?

- 43% are still in their original post-transition setting. 23% returned to a SODC and 15% died.
- 21 transitions went to a CILA and had a current status. Of these 21 transitions, 86% remained in the same setting with the same service provider. 14% of the 21 transitions returned to a SODC.

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

- Of 79 transitions from a SODC to a non-SODC setting, 17 returned back to a SODC.
- 41% returned for behavioral reasons. 29% returned from short-term therapy. 18% returned because of medical reasons. 12% returned for an “other” reason.
- About half of those who returned received technical assistance. Technical assistance means special help provided by experts. Technical assistance helps when someone has trouble after they move out of a SODC.

How are people similar or different across settings?

- Those moving to a MHC (mean age: 26.5 years) or being in jail (mean age: 33.5 years) were the youngest individuals.
- People in jail, a MHC, or family homes had lower health risks.
- People moving to institutional settings (ICF/DDs and SNFs) had the highest health risks. They also had the lowest average ICAP Service Level scores. A low ICAP score means they need more support. They had the lowest percent of mental health diagnoses.
- People who had been in SODCs the longest generally transferred to institutional settings (ICF/DDs and SNFs).

What are the characteristics of people who died in a SODC?

- 32 (mean age: 59.2 years) people died at a SODC.
- People who died had moderate to high moderate health risk. Those who died had been in the SODC for an average of 23 years. They also had the second most extensive level of support needs.

What are the characteristics of people who transitioned out of a SODC to receive short-term therapy with the expectation to return to a SODC?

- Five people moved from a SODC to a short-term nursing home.
- These individuals were on average 64 years of age and had lived in a SODC for an average of 26.5 years. They had a high moderate health risk and the second highest level of support needs.

Conclusion

This data shows the need for programs to support people with both IDD and a mental health diagnosis. Two programs that could grow are Short-Term Stabilization Homes and Support Service Teams.

More research could better understand ways to increase community capacity. More research could also ensure successful moves out of Illinois SODCs. Interviews with people who moved out of SODCs could help find what made their moves work or not work. Research on the full SODC population could be beneficial. This research may be able to tell if people who moved were different from people who stayed in SODCs.

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