

## ACCESSIBLE RESEARCH SUMMARY

### An Analysis of Movement from Illinois State-Operated Developmental Centers: Transitions between July 1, 2016 – June 30, 2022

Many people with intellectual and developmental disabilities (IDD) have lived in large residential settings. However, living in smaller community settings helps people with IDD live good lives in the way that they want.

The Institute on Disability and Human Development, University of Illinois Chicago looked at moves out of Illinois state-operated developmental centers (SODCs) from July 1, 2016 to June 30, 2022. SODCs are institutions where a lot of people with IDD live together. The study looked at the characteristics and outcomes of people who left SODCs and studied how these aspects have changed over the years.

#### How many people moved out of Illinois SODCs?

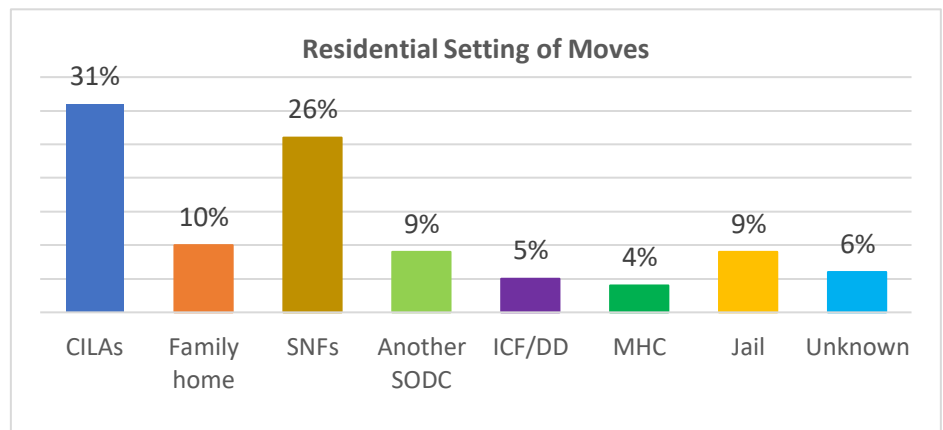
- 483 people moved. However, there were 527 moves out of SODCs since some people moved out of a SODC and came back and then moved out again. 35 people moved out twice, 3 moved out three times, and 1 moved out four times.

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

- The average age was 46 years. The average age went down between FY17 and FY20 and then up again from FY20 to FY22. On average, people lived at a SODC for 13 ½ years.
- About three in four people who moved were male. Two in three people who moved out were White. 52% had family members as their guardians and 27% had a public guardian.
- Almost two in three people had at least one mental illness. The percentage of people with a mental illness increased over the span of six years.
- Over one-third had a mild intellectual disability. On average, people needed regular personal care service and/or close supervision. Generally, people had a low to moderate health risk.

#### What type of residential setting did individuals move into?

- About one-third moved to community-integrated living arrangements (CILAs) or intermittent CILAs. 10% moved to a family setting. 26% moved to a skilled nursing facility (SNFs), 9% went to another SODC, 5% went to an intermediate care facility for developmental disabilities (ICF/DD), and 4% went to a mental health center (MHC). 9% went to jail. 6% went to an unspecified setting.

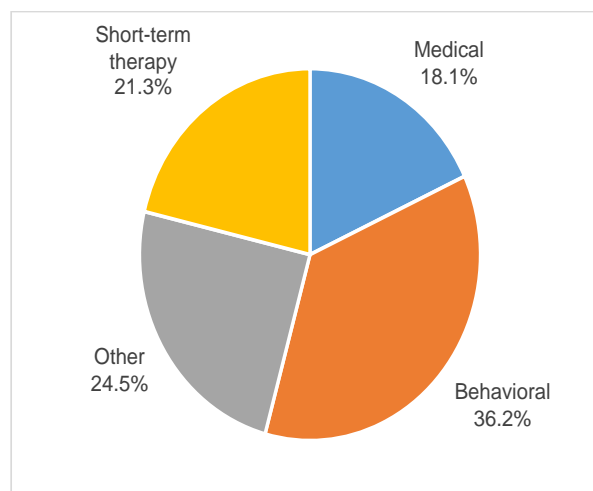


#### What extent did individuals remain in their post-transition setting?

- 43% are still in their first post-transition setting, 22% returned to a SODC, 16% went to a MHC, and 15% died.
- 160 moves were to a CILA and we know their current status. Among them, 73% remained in the same place with the same provider. 1% stayed with the same provider but moved to another place. 6% changed both providers and places but stayed in the community.
- On average, people who moved to a CILA and stayed in the community were 42 years old. They had a low to moderate health risk, an average IQ of 45, and needed regular personal care and/or close supervision.

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

- Of the 479 who moved from a SODC to a non-SODC setting, 20% returned to a SODC. The figure to the right shows why they returned.
- For those who returned for a behavioral reason, 85% received technical assistance (TA). TA means they got education or training. Of the 17 who returned for medical reasons, only one received TA. Out of the 43 people who returned after short-term therapy or for another reason, only two (6%) received TA.
- All the people who returned to a SODC from a CILA did so because of a behavioral reason.



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

- People who went to community places were generally younger than those who went to ICF/DDs and SNFs. Community places include CILAs and family places.
- People who went to ICF/DDs and SNFs had the highest health risks, more support needs, and the lowest average IQs.
- People who had been in SODCs the longest generally went to ICF/DDs and SNFs.

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

- A total of 192 people died: 146 in a SODC and 46 after leaving a SODC.
- People who died at a SODC were on average 63 years old. They had a high moderate health risk and had been in the SODC for about 25 years. They required extensive personal care and/or constant supervision. 44% had at least one mental illness and 12% had autism.
- People who died in another type of setting had a lower average IQ than those who died in SODCs. However, they needed less support.
- Those who died and for whom we don't have information on where they went were the youngest. They had been in SODCs the longest before they moved out. They needed less supports. They had the highest average IQ compared to both those who died in SODCs and other settings.

### What are the demographics and characteristics of people who transitioned out of a SODC to receive short-term therapy with the expectation that they would return to the SODC?

- 35 people moved from a SODC to a short-term nursing home to receive services. They planned to come back to the SODC.
- These individuals were on average 60 years old and had been in a SODC for 20 years. They had a moderate to high health risk, the highest level of needs, and an average IQ of 20.

Our study has two themes: 1) demographic changes around the time of the pandemic (FY20) and 2) people transitioning out have specific, significant, and sometimes increasing support needs, especially behavioral and mental health support needs.

Crabb, C., Hsieh, K., & Heller, T. (2023). *An analysis of movement from Illinois state-operated developmental centers: Transitions between July 1, 2016 – June 30, 2022*. Chicago: Institute on Disability and Human Development, University of Illinois Chicago.