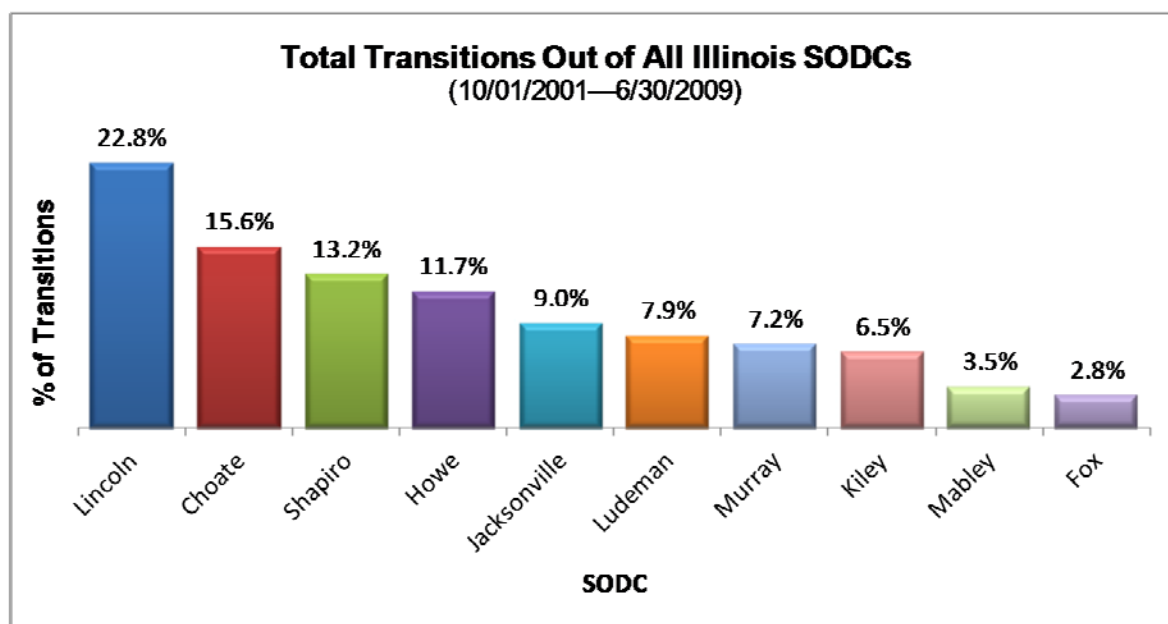


# An Analysis of Movement from State Operated Developmental Centers in Illinois

Amie Lulinski-Norris, Mary Kay Rizzolo & Tamar Heller

Since 1970, census reduction of state operated institutions has occurred at an average annual rate of 4%, resulting in the closure of 151 public institutions in 39 states (Braddock, Hemp & Rizzolo, Haffer, Tanis & Wu, 2011). Movement from institutions to community-based settings has been a focus of numerous studies both nationally and in Illinois (see Braddock, Heller & Zashin, 1984; Fujiura, Fitzsimons-Cova & Bruhn, 2002; Heller, Factor & Braddock, 1986).

In 2010, the Department of Human Services' Division of Developmental Disabilities (DHS-DDD) engaged the Institute on Disability and Human Development (IDHD) to examine outcomes for individuals transitioning out of Illinois' nine State Operated Developmental Centers (SODCs) between October 1, 2001, and June 30, 2009. The study was guided by seven research questions, presented below, with the intent to obtain information on where people moved and how they fared.



**QUESTION 1: How many individuals moved out of Illinois SODCs between October 1, 2001 and June 30, 2009?**

Between October 1, 2001 and June 30, 2009, **1,594** individuals moved out of an Illinois SODC into another placement. The SODC with the highest number of transitions was Lincoln, while Fox had the least.

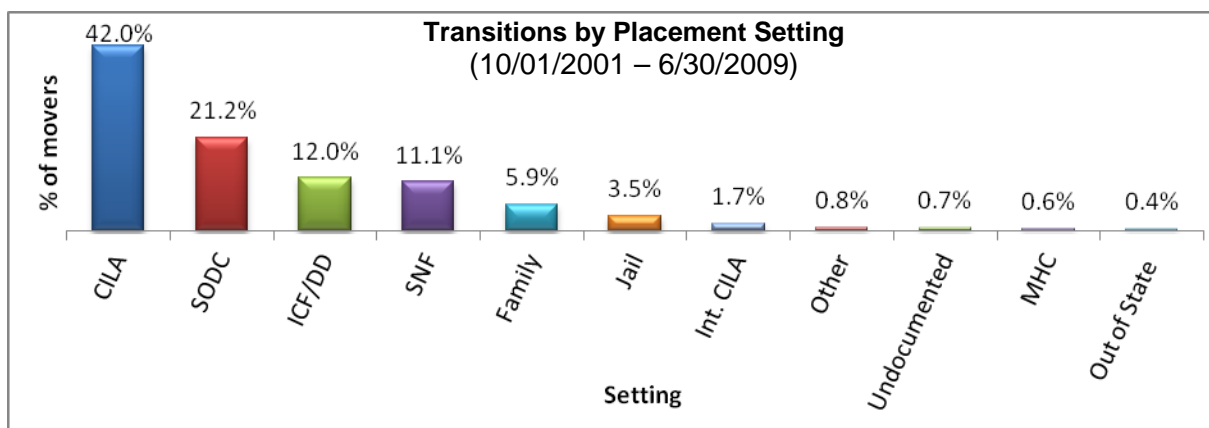
## **QUESTION 2: What were the characteristics of those who moved out of IL SODCs?**

Of the 1,594 individuals who moved:

- The average age was 47 (ranging from 16-95);
- The majority (66.3%) were men;
- Nearly half (46.7%) had a psychiatric diagnosis when they moved;
- 45.2% had a diagnosis of profound intellectual disability, while 16.9%, 16.1% and 20.1% had a severe, moderate, or mild level of intellectual disability, respectively;
- The average ICAP Adaptive Behavior score of those who moved was 52.2 months (approximately 4.4 years) with a range of 1-336 months;
- The average ICAP Service Level Score was 44.9 (ranging from 1-98), which indicates they needed extensive personal care and constant supervision; and
- The average Health Risk Screening Tool (HRST) care level was 2.52 (ranging from 1-6), meaning that the average person had a low to moderate degree of health risk.

## **QUESTION 3: Where did people move?**

- 50.6% of the people moved from an SODC into a community setting [i.e., 24 hour Community Integrated Living Arrangements (CILA), Intermittent CILA, Family Home];



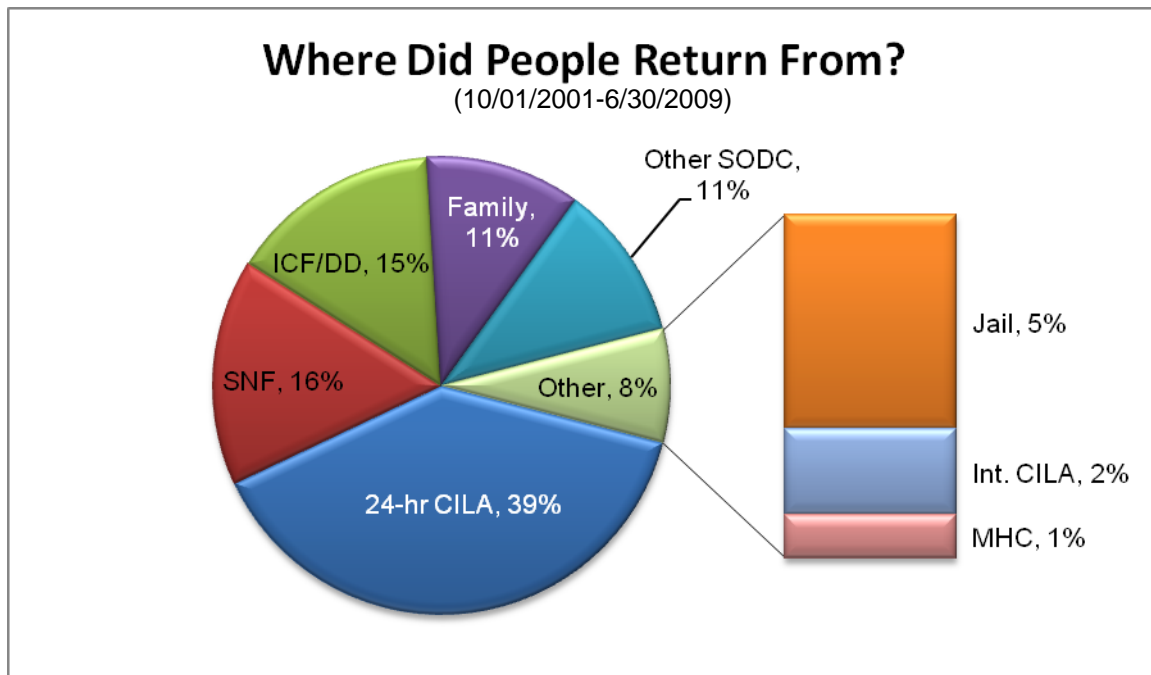
- 49.4% of the individuals moved from an the SODC into another congregate setting [i.e., another SODC, Skilled Nursing Facility (SNF), Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD), State Operated Mental Health Center (MHC), or Jail]; and
- Individuals who moved into a community-based setting were more likely to have a psychiatric diagnosis than their counterparts who moved into another congregate setting.

## **QUESTION 4: Did people stay in the place they moved to?**

- As of June 30, 2009, over half (53.5%) of the individuals were still being supported by the residential provider to which they moved;
- 6.0% changed residential providers;
- 10.2% returned to an SODC;
- 11.5% died; and
- SODCs did not have information on the current status of 18.8% of the individuals who transitioned out.

**QUESTION 5: What were the characteristics of the persons who returned to an SODC as compared to those who remained in a community setting?**

- 163 (10.2%) individuals returned to an SODC after moving out.
  - ⇒ 72.2% returned to an SODC due to behavioral reasons;
  - ⇒ 32.5% received some type of Technical Assistance<sup>1</sup> (TA) from DHS: and
  - ⇒ 97% of TA provided to returners was to address behavioral concerns.



- As compared to those returning to an SODC, **persons who remained living in the community setting to which they transitioned:**
  - ⇒ Were significantly older;
  - ⇒ Had significantly lower ICAP Adaptive Behavior scores;
  - ⇒ Had significantly lower ICAP Service Level scores;
  - ⇒ Had a significantly lower health risk; and
  - ⇒ Had a significantly shorter length of previous stay at an SODC.
- Presence of a psychiatric diagnosis was not statistically significant between groups; 46% of those remaining in their community placement and 54% of those returning to an SODC had a psychiatric diagnosis.

### **QUESTION 6: How did personal characteristics compare across residential settings?**

- Overall, there was a significant difference between type of residential setting with respect to the individual's age, HSRT scores, ICAP Behavioral and Service Level scores, IQ, and length of stay at SODC between groups.
  - ⇒ As compared to people who moved from an SODC into another congregate setting, **persons who moved into community settings** were typically younger, had a higher IQ, higher ICAP Adaptive Behavior score and higher Service Level Score. They tended to have a lower HSRT score and a shorter previous length of stay in the SODC. Those who moved into a community based setting, however, were more likely to have a psychiatric diagnosis.
  - ⇒ **Persons who moved into a nursing home** tended to be significantly older, have a significantly lower IQ, lower ICAP Adaptive Behavior score and lower Service Level score than individuals who moved to other settings. They were at a significantly higher health risk and were less likely to have a psychiatric diagnosis.

### **QUESTION 7: What were the characteristics of the individuals who died since transition?**

- During the study period, the only significant difference between individuals who died in an SODC and those individuals who died post-transition was with respect to HRST scores and length of stay. **Individuals dying post-transition had a significantly higher health risk as well as a significantly longer previous stay at an SODC as compared to their counterparts.**

## **THEMES**

**Theme 1:** The majority of deaths over the entire eight year study period occurred in SODCs, while the majority of post-transition deaths occurred in Skilled Nursing Facilities.

**Theme 2:** The most frequent reason for return to SODCs across all centers was due to behavioral issues, warranting analysis of the type, severity and duration of the particular behaviors contributing to return as well as examination of the accessibility, delivery, and effectiveness of related community-based behavioral supports in Illinois.

<sup>1</sup> For the purposes of this report, technical assistance (TA) is defined as supports offered to individuals transitioning out of an SODC that fall outside of the parameters of routine follow-up.