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

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Acronyms

ASD: Autism spectrum disorder

CILA: Community Integrated Living Arrangement

DHS-DDD: Illinois Department of Human Services – Division of Developmental Disabilities

HRST: Health Risk Screening Tool

ICAP: Inventory for Client and Agency Planning

ICF/DD: Intermediate Care Facility for Developmental Disabilities

ID: Intellectual disability

IDD: Intellectual and developmental disability

IDHD: Institute on Disability and Human Development

LOS: Length of stay

MHC: Mental Health Center

PDD: Pervasive Developmental Disorder

SNF: Skilled nursing facility

SODC: State-Operated Developmental Center

TA: Technical assistance

Executive Summary

The Illinois Department of Human Services, Division of Developmental Disabilities (DHS-DDD) contracted with the Institute on Disability and Human Development (IDHD) at the University of Illinois Chicago to conduct an analysis of transitions out of State-Operated Developmental Centers (SODCs) from July 1, 2020 – June 30, 2021. Data were collected and analyzed to determine characteristics of and outcomes for people transitioning out of SODCs in Illinois. Prior to this project, studies investigating transitions across all Illinois SODCs from October 1, 2001 through June 30, 2008 (Lulinski-Norris et al., 2010), from July 1, 2008 through June 30, 2009 (Lulinski-Norris et al., 2012), from July 1, 2009 through June 30, 2012 (Vasudevan et al., 2015), from January 1, 2013 through June 30, 2016 (Owen et al., 2017), from July 1, 2016 through December 31, 2018 (Crabb et al., 2020), and from July 1, 2016 through June 30, 2020 (Crabb et al., 2021) were conducted. This project is a continuation of those studies for the purpose of identifying trends related to depopulation of SODCs in Illinois. All data reported is as of March 2022.

Findings

Question 1. How many transitions occurred out of SODCs?

- There were 84 live transitions out of SODCs in this timeframe representing 82 people, as two people transitioned twice.
- Together, Shapiro, Choate, and Kiley (n = 70 transitions) accounted for over 80% of the total live transitions out of SODCs.

Question 2. What are the demographics and characteristics of those who transitioned out of SODCs?

- The average age of the 82 people who transitioned out of SODCs (live transitions) was 47.3 years of age, and the majority (73.2%) were male. Slightly more than half (52.4%) of people had family members as their guardian, while 28.0% had a public guardian, and 17.1% were their own guardian. On average, people had lived in the SODC for 14.5 years, ranging from a few weeks to over 53 years. Most people (69.5%) were White.
- Over two-thirds (70.7%) of people who transitioned had at least one psychiatric diagnosis. The most common psychiatric diagnoses were mood (32.9%), psychotic (14.6%), and anxiety (14.6%) disorders. In addition to psychiatric diagnoses, 19.5% of people were diagnosed with autism spectrum disorder (ASD) and 3.7% were diagnosed with Pervasive Developmental Disorder (PDD).
- People had varying levels of intellectual disability (ID). The largest percentage of individuals had mild ID (31.7%) followed by profound ID (28.0%). People who transitioned had an average Inventory for Client and Agency Planning (ICAP)

Service Level score of 54.4, putting them in service level 3 (out of 5), which indicates a need for “regular personal care and/or close supervision.” They also had a mean Health Risk Screening Tool (HRST) level of 2.6 (between low and moderate risk) and about a third (30.5%) had high health risks (≥ 4 HRST score).

- Together, these characteristics indicate that people who transitioned had a variety of disability and psychiatric diagnoses along with personal care and health needs. It is not possible for the evaluation team to assess whether these demographic characteristics differed from the population of people remaining in SODCs.

Question 3. To what type of residential setting did individuals transition? (n = 84 transitions)

- Of the 84 live transitions, the greatest percentage (26.2%) went to skilled nursing facilities (SNFs) followed by CILAs, or Community Integrated Living Arrangements (25.0%). Approximately 17.9% of transitions went to family settings, followed by 9.5% to jail; 6.0% went to another SODC, another 6.0% went to an Intermediate Care Facility for Developmental Disabilities (ICF/DD), and 2.4% went to a State-Operated Mental Health Center (MHC). The remaining 7.1% transitioned to other settings.
- Half of transitions from Shapiro went to CILAs.

Question 4. To what extent did individuals remain in their post-transition setting?

- SODC staff follow-up with people who have transitioned for 12 months after their transition; because of those who transitioned more than a year ago, of the 84 transitions, 19.1% have an unknown or missing current status. 42.9% of transitions had a continuous placement, meaning that they were still in the original transition setting. 22.6% returned to a SODC, and 15.5% died following their transition out of a SODC.
- Of the 21 transitions that went to a CILA and who had a current status, 85.7% remained in the same setting and with the same service provider (continuous placement) and 14.3% returned to a SODC.
- Of people who originally transitioned to and remained in a CILA (n = 18), they were middle-aged (46.1 years on average), had an average HRST score of 2.7 (low to moderate health risk), had an average IQ of 31.7, and had an average ICAP Service Level score of 57.0 (Level 3 – regular personal care and/or close supervision).

Question 5. Why did people return to a SODC and did they receive technical assistance (TA)?

- Of the 79 transitions from a SODC to a non-SODC setting, 17 (21.5%) ultimately returned to a SODC. The main reason for return was behavioral (41.2%), followed by short-term therapy (29.4%), medical (17.6%), and other (11.8%).
- Technical assistance (TA) was provided to all seven returns for a behavioral reason (behavioral TA). TA was not provided to any of those returning because of a medical reason or short-term therapy (n = 8). One of the two that returned for another reason received medical TA while the other did not receive any TA.

Question 6. How do the demographics and characteristics of people who transitioned compare across residential settings?

- Of the 82 people who transitioned out of SODCs, the youngest individuals were those who went to a MHC (mean age = 26.5 years) and those who went to jail (mean age = 33.5 years). People who had been in SODCs the longest generally transferred to other institutional settings including ICF/DDs and SNFs.
- Those transitioning to jail, a MHC, or a family setting had lower health risks than other transition settings. People who went to jail had the highest ICAP service level scores indicating the lowest level of support need. People transitioning to ICF/DDs and SNFs had the lowest percentage of psychiatric diagnosis.

Question 7. What are the demographics and characteristics of people who died in a SODC?

- A total of 32 people died at a SODC. People who died had a mean age of 59.2 years, a mean HRST of 3.8 (moderate to high moderate health risk), and had been in the SODC for an average of 23.3 years. They also had an average ICAP Service Level score of 32.8, a score which represents the second most extensive level of support needs.
- 50.0% had at least one psychiatric disorder and 15.6% had an ASD diagnosis.

Question 8. What are the demographics and 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 to receive services with the expectation that they would ultimately return to a SODC.
- These individuals were on average 64.2 years of age with an average length of stay (LOS) in a SODC of 26.5 years. Additionally, they had a mean HRST score of 4.0 indicating a high moderate health risk and a mean ICAP Service Level score of 34.6 which indicates the second highest level of support needs. Their mean IQ was 26.4.
- These individuals had significant health and personal support needs.

Introduction

People with intellectual and developmental disabilities (IDD) have historically resided in large congregate settings like State-Operated Developmental Centers (SODCs) and nursing facilities that prioritized medical care. In 1967, the institutional census of people with IDD peaked and began its subsequent decline (Scott et al., 2008). The movement of deinstitutionalization of people with IDD, or transitioning people out of large congregate facilities and into smaller community settings, has gained traction ever since. Community living is generally touted as the paragon of habilitation for people with IDD across the spectrum of support needs. The *State of the States in Developmental Disabilities* project tracks state spending on people with IDD in community settings and in SODCs. As of June 30, 2018, 115 institutions were open across the United States compared to 376 between 1960 and 2017 (Larson et al., 2021).

Despite closing four SODCs since 1982, most recently the Jacksonville Developmental Center in 2012, Illinois continues to have one of the highest rates of institutionalization of people with IDD in the United States. This report includes data on people who transitioned out of a SODC during FY2021, a timeframe when Illinois had seven active SODCs.

Research has tied transitions out of institutions and into the community to positive outcomes (Chowdhury & Benson, 2011; Heller et al., 2008; Kozma et al., 2009; Lakin et al., 2011; Rizzolo et al., 2016; Stancliffe & Lakin, 2006). However, providing services in the community for people with IDD is limited by barriers such as Medicaid funding constraints, labor shortages, political pressure opposed to deinstitutionalization, and a shortage of affordable and accessible housing (Kaiser Commission on Medicaid and the Uninsured, 2004). Additionally, proponents of deinstitutionalization argue that it costs states less to support individuals in the community than in institutional settings and that many people with IDD have better outcomes and a higher quality of life in the community. However, inadequate community capacity to support people with IDD in the community limits transitions to the community from SODCs, particularly in Illinois (Lulinski & Heller, 2021; Lulinski-Norris, 2014).

The Institute on Disability and Human Development (IDHD) at the University of Illinois Chicago has maintained a database of transitions out of SODCs in Illinois since 2001. The last report in this series was completed in 2021 (Crabb et al., 2021) and in the spring of 2022, the Illinois Department of Human Services, Division of Developmental Disabilities (DHS-DDD) extended the database to include transitions from July 1, 2020 through June 30, 2021. The current report is very similar to previous reports in this series and asks the same primary questions (see the Methodology section), and aims to inform policymakers of the state and of the SODCs to improve transition planning in the future.

The questions that this report answers, for the time period of July 1, 2020 – June 30, 2021, are:

1) How many transitions occurred out of SODCs?
2) What are the demographics and characteristics of those who transitioned out of SODCs?
3) To what type of residential setting did individuals transition?
4) To what extent did individuals remain in their post-transition setting?
5) Why did people return to a SODC and did they receive technical assistance (TA)?
6) How do the demographics and characteristics of people who transitioned compare across residential settings?
7) What are the demographics and characteristics of people who died in a SODC?
8) What are the demographics and characteristics of people who transitioned out of a SODC to receive short-term therapy with the expectation to return to a SODC?

Methods

The current project investigated outcomes of individuals who moved out of Illinois' SODCs between **July 1, 2020 and June 30, 2021** using the same methods as used in previous studies that covered the time periods from October 1, 2001 – June 30, 2008 (Lulinski-Norris et al., 2010), July 1, 2008 – June 30, 2009 (Lulinski-Norris et al., 2012), July 1, 2009 – June 30, 2012 (Vasudevan et al., 2015), January 1, 2013 – June 30, 2016 (Owen et al., 2017), July 1, 2016 – December 31, 2018 (Crabb et al., 2020) and July 1, 2016 – June 30, 2020 (Crabb et al., 2021).

Data was gathered by the Illinois DHS-DDD from each of the SODCs. In order to maintain confidentiality, data was de-identified before being submitted to IDHD. Data gathered included the following information as of March 2022:

1) Date of birth
2) SODC individual transitioned from
3) Gender
4) Race
5) Ethnicity
6) Date of admission to SODC
7) Whether the admission to a SODC was a short-term admission
8) Date individual transitioned from SODC (discharge date)
9) Health Risk Screening Tool (HRST) level
10) Inventory for Client and Agency Planning (ICAP) Adaptive Behavior Scores (Motor Skills, Social and Communication Skills, Personal Living, Community Living, and Broad Independence)
11) ICAP Service Level Score
12) ICAP Maladaptive Behavior Scores (Internal, Asocial, Externalized, and General)
13) IQ at time of transition
14) Presence and level of intellectual disability (ID)
15) Presence of autism spectrum disorder and diagnosis
16) Psychiatric diagnoses
17) Name of setting to which the individual transitioned and zip code
18) Type of post-transition setting
19) Number of residents residing in post-transition setting
20) Guardianship status
21) Current status of individual's location
22) Whether or not individual returned to a SODC and reason for return
23) Provision and type of technical assistance (TA) post-transition

Data was coded and then analyzed using SPSS Statistics 26.0 software. This report presents results of that analysis including descriptive information and basic comparisons between transition groups.

Results

The results of this evaluation are organized around the eight questions noted in the Introduction to this report. The time frame for the data below is **July 1, 2020 through June 30, 2021**.

Question 1. How many transitions occurred out of SODCs?

There were 84 live transitions out of the Illinois SODC system during the entire time period. These transitions represented 82 people, as two people transitioned twice during the time period. Questions one through six focus on these 84 live transitions representing 82 people, while question seven focuses on transitions from SODCs where the person died in the SODC during this period (32 people). Question eight focuses on five people who transitioned out of SODCs into short-term nursing homes with the expectation that they would ultimately return to the SODC they were discharged from.

Table 1. SODC Transitions (n = 84)

SODC	n	%
Choate	25	29.8
Fox	1	1.2
Kiley	19	22.6
Ludeman	9	10.7
Mabley	3	3.6
Murray	1	1.2
Shapiro	26	31.0

As shown in Table 1, the Governor Samuel H. Shapiro Developmental Center (Shapiro) accounted for the most transitions over this period (n = 26, 31.0%). The second highest number of transitions were from Choate Developmental Center (Choate) with 25 (29.8%) transitions. Kiley Developmental Center (Kiley) transitioned 22.6% of the total transitions. Together, Shapiro, Choate, and Kiley accounted for over 80% of the total transitions from SODCs in Illinois. The remaining SODCs, including Ludeman Developmental Center (Ludeman), Jack Mabley Developmental Center (Mabley), Fox Developmental Center (Fox), and Murray Developmental Center (Murray), each accounted for between 1.2% and 10.7% of the total transitions.

Question 2. What are the demographics and characteristics of those who transitioned out of SODCs?

Table 2 provides an overview of age, length of stay (LOS) in the SODC, gender, race, and guardianship status for individuals who transitioned out of SODCs. For the two individuals that transitioned twice during the time period, only their most recent live transition was used to calculate demographics. The research team only had access to data on people who transitioned, so we cannot determine whether or not these characteristics are statistically different from the characteristics of the SODC population as a whole.

Age

Age was calculated from the time of transition. Of the 82 individuals who transitioned out of SODCs, the youngest was 20 and the oldest was 100 years. The average age was 47.3 (SD = 17.4) years.

Table 2. Demographics (n = 82)

Demographic	Mean	SD
Age	47.3	17.4
LOS	14.5	17.0
	n	**%**
Gender		
Male	60	73.2
Female	22	26.8
Race		
White	57	69.5
Non-White	25	30.5
Guardianship		
Own	14	17.1
Public	23	28.0
Family	43	52.4
Non-Family	2	2.4

Length of Stay (LOS)

People who transitioned out of a SODC had lived in the SODC for an average of 14.5 years, ranging from a few weeks to over 53 years (SD = 17.0).

Gender

Most of the individuals (73.2%) who transitioned out of the SODCs were male.

Race

Most people (69.5%) who transitioned out of SODCs were White.

Guardianship Status

Slightly more than half (52.4%) of individuals had family members as their guardians. More than a quarter (28.0%) of the 82 individuals that transitioned had a public guardian and about 17% were their own guardian or deemed legally competent. Only two (2.4%) had a private non-family member guardian.

Table 3. Psychiatric Diagnoses (n = 82)

	n	%
Number of psychiatric diagnoses		
0	24	29.3
1	36	43.9
2	14	17.1
3	5	6.1
4	2	2.4
5	1	1.2
Psychiatric diagnosis*		
Psychotic	12	14.6
Impulse	8	9.8
Anxiety	12	14.6
Mood	27	32.9
Personality	7	8.5
Childhood	8	9.8
Adjustment	1	1.2
***Not mutually exclusive**		

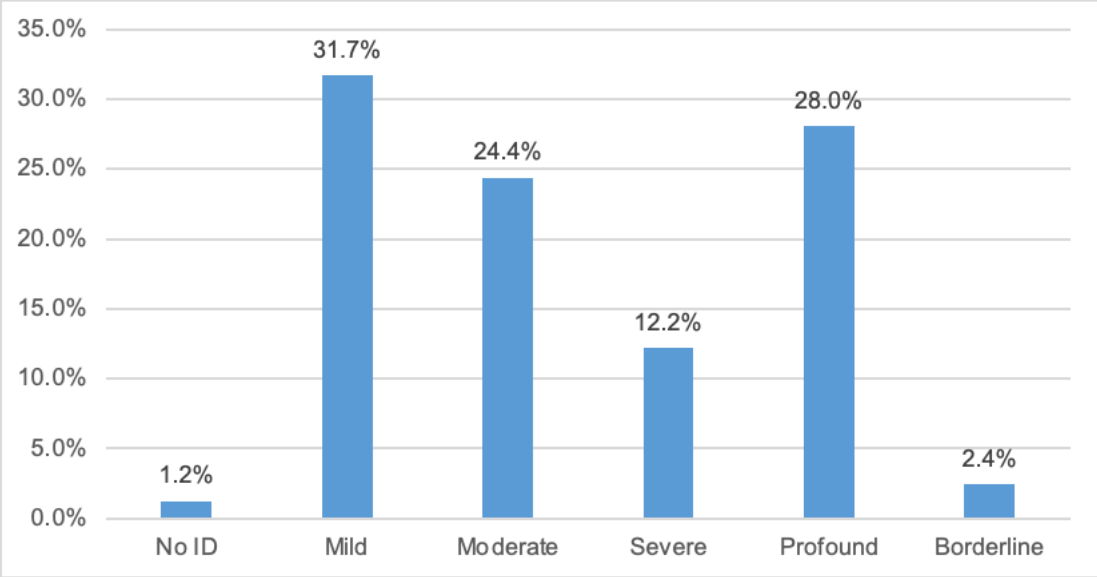
Psychiatric Diagnosis

Table 3 shows the number of psychiatric diagnoses and the type(s). The majority (70.7%) had at least one psychiatric diagnosis; over a third (43.9%) had one psychiatric diagnosis and 26.8% had two or more psychiatric diagnoses. The most common psychiatric diagnoses were mood disorder (32.9%), psychotic disorder (14.6%), anxiety disorders (14.6%), impulse control disorder (9.8%), childhood disorders (9.8%), personality disorders (8.5%), and adjustment disorders (1.2%).

Level of Intellectual Disability (ID)

Figure 1 illustrates the level of ID. Of the 82 individuals who transitioned out of a SODC, all but one (1.2%) had a diagnosis of ID. Almost one third (31.7%) of those who transitioned during the time period had a mild ID. Profound was the next highest category (28.0%) followed by moderate (24.4%), severe (12.2%), and borderline (2.4%).

Figure 1. Level of ID (n = 82)



Autism Spectrum Disorder (ASD) Diagnosis

19.5% of people who transitioned had a diagnosis of ASD and 3.7% had pervasive developmental disorder (PDD), see Table 4.

Table 4. Frequency of ASD Diagnosis (n = 82)

ASD Dx	n	%
No ASD Dx	63	76.8
ASD	16	19.5
PDD	3	3.7

Inventory for Client and Agency Planning (ICAP) Adaptive Behavior Domain Scores

Table 5. ICAP Adaptive Behavior Domain Scores (n =82)

Adaptive Area	Mean
Motor Skills	436.1
Social & Communication Skills	450.1
Personal Living	472.7
Community Living	452.2
Broad Independence	452.9

Table 5 shows the average ICAP Adaptive Behavior Domain scores. The lowest ICAP Adaptive Behavior Domain score was in the area of Motor Skills (436.1) while the highest was in the area of Personal Living (472.7). A score of 500 represents a performance level roughly equal to that of a non-disabled child who is 10 years, 4 months of age, or performing at the fifth grade level. These scores indicate deficits in each area of Adaptive Behavior.

ICAP Service Level Scores

The ICAP Service Level Score is a combination of adaptive behavior scores and maladaptive behavior scores. ICAP Service Level Scores range from 0 to 100 and indicate the need for various levels of support (higher scores indicate a lower level of assistance needed), listed in the table below.

Level	Score	Description
1	1-29	Total personal care and intense supervision
2	30-49	Extensive personal care and/or constant supervision
3	50-69	Regular personal care and/or close supervision
4	70-89	Limited personal care and/or regular supervision
5	90+	Infrequent or no assistance for daily living

The range of ICAP Service Level Scores was 12 - 90. The average ICAP Service Level Score for individuals who transitioned was 54.4 (SD = 21.5), which indicates an average need (Level 3) for regular personal care and close supervision.

ICAP Maladaptive Behavior Domain Scores

Table 6. ICAP Maladaptive Behavior Domain Scores (n = 82)

Maladaptive Area	Mean
Internalized	-7.0
Asocial	-9.4
Externalized	-9.7
General	-12.0

Table 6 shows the average ICAP Maladaptive Behavior Domain scores. Maladaptive Behavior Domain scores range from +10 to -41 and below. Overall, the General Score was the lowest (-12.0) while the Internalized score was the highest (-7.0). The General Maladaptive Behavior Score is the lowest and represents a marginally serious maladaptive behavior. The remaining scores are all within the normal limits.

Level	Risk
Level 1	Lowest Risk
Level 2	Low Risk
Level 3	Moderate Risk
Level 4	High Moderate Risk
Level 5	High Risk
Level 6	Highest Risk

Health Risk Screening Tool (HRST)

The HRST was designed to screen for health risks associated with disabilities and is determined by rating an individual's risk and care levels across five domains: functional status, behavior, physiology, safety, and frequency of services. The final HRST score indicates health care levels and degrees of health risk for the individual, ranging from level 1 to level 6 (see the Table displayed on the left).

Table 7 shows the percentage of people with high HRST scores (≥ 4) and the mean HRST score. HRST scores for individuals who transitioned during the study period range from

Table 7. HRST Health Risk Levels (n = 82)

HRST	
% High HRST (≥ 4)	30.5%
Mean HRST	2.6

level 1 to level 6 and the average HRST score was 2.6 (SD = 1.6), which is between the low to moderate risk levels. Nearly a third (30.5%) had a high HRST score of greater than or equal to Level 4.

Question 3. To what type of residential setting did individuals transition?

Table 8 describes the percentage of transitions (n = 84) from each SODC to various types of residential settings. Though post-transition settings varied by SODC, transitions out of a SODC and into a skilled nursing facility (SNF) made up over a quarter (26.2%) of the 84 transitions. The second most common post-transition setting was Community Integrated Living Arrangement (CILA) which made up 25.0% of the transitions. Approximately 17.9% of transitions went to family settings, followed by 9.5% of transitions to jail; 6.0% went to another SODC, another 6.0% went to an Intermediate Care Facility for Developmental Disabilities (ICF/DD), and 2.4% went to a State-Operated Mental Health Center (MHC). The remaining 7.1% went to other settings.

Shapiro had the highest percent of transitions that went to CILAs (50.0%) while Fox, Mabley, and Murray had no transitions to CILAs, though the transition numbers were less than three for each of these centers.

Table 8. Percentage of Discharge Setting by SODC Discharged From (n = 84)

Setting	Choate (n = 25)	Fox (n = 1)	Kiley (n = 19)	Ludeman (n = 9)	Mabley (n = 3)	Murray (n = 1)	Shapiro (n = 26)	Total (n = 84)
CILA	12.0	-	21.1	11.1	-	-	50.0	25.0
ICF	8.0	-	-	11.1	-	-	7.7	6.0
Other SODC	4.0	-	-	22.2	-	-	7.7	6.0
MHC	8.0	-	-	-	-	-	-	2.4
SNF	-	-	57.9	44.4	-	-	26.9	26.2
Jail	32.0	-	-	-	-	-	-	9.5
Family	28.0	-	10.5	11.1	66.7	100.0	7.7	17.9
Other	8.0	100.0	10.5	-	33.3	-	-	7.1

Question 4. To what extent did individuals remain in their post-transition setting?

Regulations only require the Department of Human Services to follow individuals for one year after they transitioned. Because data for this report covers July 1, 2020 – June 30, 2021, the SODCs from which individuals transitioned were not required to track the current living situation of many of these individuals at the time data was provided (March 2022). As a result, the current status of 16.7% of the transitions during this period are unknown and 2.4% are missing. Of those

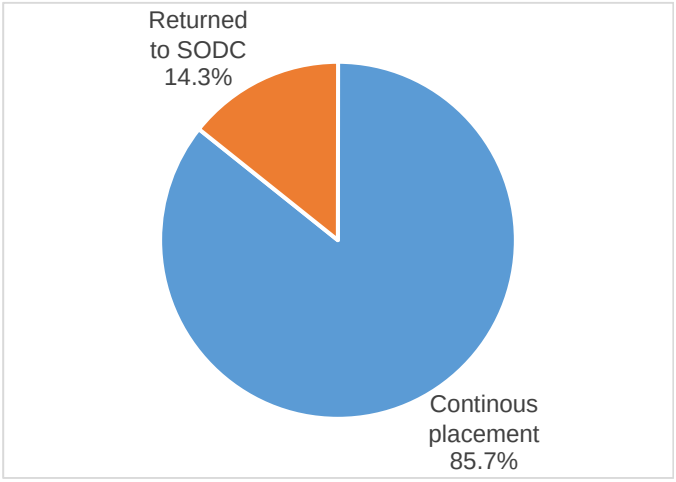
Table 9. Current Status of Transitioned Individuals (n = 84)

Current Status	%
Continuous placement	42.9
Returned to SODC	22.6
Deceased	15.5
Unknown	16.7
Missing	2.4

for whom data was available, 42.9% had maintained a continuous placement in their new setting following that transition (Table 9).

Of the 21 transitions from a SODC to a CILA (**Error! Reference source not found.**) with a current status, 85.7% remained in the same post-transition placement. The remaining 14.3% returned to a SODC.

Figure 2. Current Status of Transitions from a SODC to a CILA (n = 21)



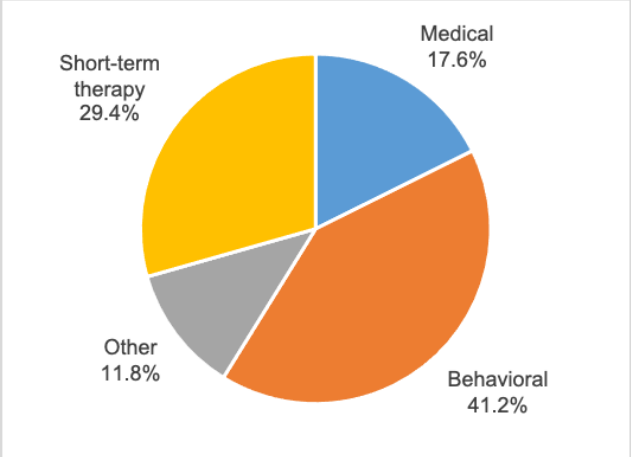
Individuals who went to a CILA and remained there (n = 18) had a mean age of 46.1 years, mean HRST score of 2.7 (low to moderate health risk), mean IQ of 31.7, and a mean ICAP Service Level score of 57.0 (average need for regular personal care and close supervision, see Table 10.

Table 10. Characteristics of Transitions to and Remained in the Community (n = 18)

Characteristic	Mean
Age (years)	46.1
HRST	2.7
IQ	31.7
ICAP Service Level	57.0

Question 5. Why did people return to a SODC and did they receive TA?

Figure 3. Reasons for Return to a SODC from a Non-SODC Post-Transition Setting (n = 17)



Of the 79 transitions from a SODC to a non-SODC setting, 17 ultimately returned to a SODC (21.5%). The discharge summary sheet had the following response options for reason for return to a SODC: medical, behavioral, discharged for short-term therapy which concluded, or other. **Error! Reference source not found.** illustrates the reasons for return to a SODC after discharge. The main reason for return was behavioral (41.2%), followed by short-term therapy (29.4%), medical (17.6%), and other (11.8%).

For the purposes of this report, technical assistance (TA) is defined as supports offered to individuals transitioning out of a SODC that fall outside of the parameters of routine follow-up. Such routine follow-up is called Direct Linkage and Aftercare and is outlined in Illinois Administrative Code, Title 59, Chapter 1, Part 25 entitled "Recipient Discharge/Linkage/ Aftercare." TA is support provided in addition to Direct Linkage and Aftercare and is offered for individuals experiencing behavioral and/or medical concerns for which the service provider requires input from a specific discipline. TA may include: face-to-face visits by a staff member familiar with the individual; observation, evaluation, and provision of recommendations by discipline-specific professionals to address identified issues; a focused review of past records, information gathering, information dissemination, training, consultation, and related activities; or a conference call with an interdisciplinary team from the SODC and community provider, as well as DHS-DDD staff. Available information on TA was limited to whether or not it was provided for medical, behavioral, medical and behavioral, or dietary issues but did not specify how the support was delivered.

Table 11. Receipt of TA for SODC Returners by Center (n = 17)

SODC	Number Receiving TA	Number of Returns	Percent Receiving TA
Choate	1	3	33.3%
Fox	-	0	-
Kiley	1	7	14.3%
Ludeman	1	2	50.0%
Mabley	0	1	0.0%
Murray	-	0	-
Shapiro	4	4	100.0%
Total	7	17	41.2%

Table 11 shows the number of transitions that returned to a SODC, along with the percent of those returns receiving TA. Kiley (7) and Shapiro (4) had the highest number of returns with only one (14.3%) of those receiving TA at Kiley and all four (100.0%) receiving TA at Shapiro. Choate had three returns, one of which received TA (33.3%). Ludeman had two returns and one was provided with TA (50.0%). The one return to Mabley did not receive TA.

Figure 4 compares the reason (medical, behavioral, other, and short-term therapy) for a return to a SODC by whether or not they received medical, behavioral, or medical and behavioral TA. Of the three transitions back to a SODC because of medical reasons, none received TA. Conversely, for those seven who returned to a SODC because of behavioral reasons, all received behavioral TA. Of the remaining seven transitions (two for other reasons and five due to a short-term therapy return), one received medical TA.

Figure 4. Reason for Return to SODC from a Non-SODC Post-Transition Setting by TA Received (n = 17)

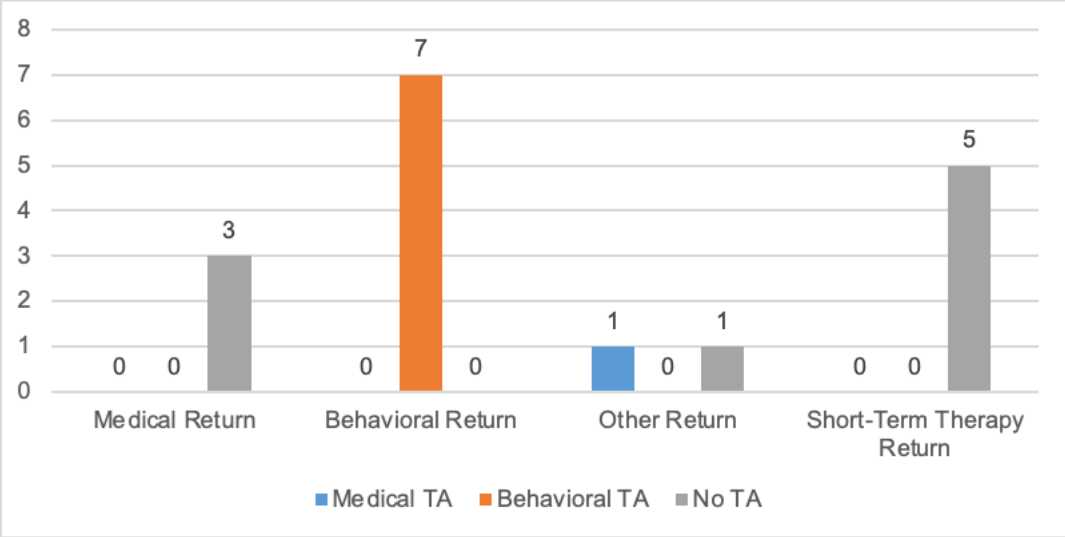


Table 12 compares the reason (medical, behavioral, other, and short-term therapy), for a return to a SODC by the setting from which they returned to the SODC. Those that returned from a CILA, family home, or ICF/DD did so for behavioral reasons (100.0%). The individual who returned from a MHC returned from short-term therapy, as did four of those who returned from a SNF (57.1%). Three of the seven returners from SNFs did so for medical reasons (42.9%). Of the two individuals who were discharged to another setting, they both returned for another reason.

Table 12. Reason for Return to a SODC by Non-SODC Post-Transition Placement (n = 17)

Reason for Return	24-Hour CILA (n = 3)	Family Home (n = 2)	ICF/DD (n = 2)	MHC (n = 1)	SNF (n = 7)	Other (n = 2)
Medical	-	-	-	-	3 (42.9%)	-
Behavioral	3 (100.0%)	2 (100.0%)	2 (100.0%)	-	-	-
Other	-	-	-	-	-	2 (100.0%)
Short-term therapy	-	-	-	1 (100.0%)	4 (57.1%)	-

Question 6. How do the demographics and characteristics of people who transitioned compare across residential settings?

For the two individuals that transitioned twice during the study period, the most recent date of discharge was used to compute the characteristics and demographics shown below. The youngest individuals who transitioned out of SODCs were those who went to a MHC (mean age = 26.5) and those who went to jail (mean age = 33.5). People who had been in SODCs the longest generally transferred to other institutional settings including ICF/DDs and SNFs. Those transitioning to jail, a MHC, or a family setting had lower health risks than other transition settings. People who went to jail had the highest ICAP service level scores indicating the lowest level of support need. People transitioning to ICF/DDs and SNFs had the lowest percentage of psychiatric diagnosis. People transitioning out of SODCs and into CILAs (33.3%), ICF/DDs (40.0%) and MHCs (100.0%) had the highest percentage of an autism diagnosis (Table 13).

Table 13. Comparing Characteristics of Transitions by Post-Transition Residential Setting (n = 82)

Characteristic	CILA (n = 21)	ICF/DD (n = 5)	SODC (n = 5)	MHC (n = 2)	SNF (n = 20)	Jail (n = 8)	Family (n = 15)	Other (n = 6)
	mean							
Age	46.1	59.2	35.0	26.5	63.2	33.5	39.1	44.8
LOS	11.6	27.2	11.9	0.2	24.5	0.7	10.7	15.4
HRST	2.6	4.0	2.2	1.0	3.9	1.0	1.9	2.5
ICAP Service Level	57.0	36.2	58.4	67.5	35.3	75.5	63.9	64.8
IQ	32.0	32.0	47.8	79.0	10.2	60.5	48.3	33.5
	Percent %							
Psych Dx	85.7	40.0	80.0	100.0	50.0	62.5	80.0	83.3
ASD Dx	33.3	40.0	20.0	100.0	10.0	25.0	20.0	0.0

Question 7. What are the demographics and characteristics of people who died in a SODC?

A total of 32 people died at a SODC. Table 14 shows the demographic characteristics of individuals who died. On average, individuals that died in a SODC were 59.2 years of age, had an ICAP service level score of 32.8 (indicating a higher level of support needed), had a moderate to high moderate health risk (mean HRST score = 3.8), and had an IQ of 22.5. These individuals lived in a SODC for an average of 23.3 years until their death. Half of the individuals who died had at least one psychiatric diagnosis and 15.6% had autism.

Table 14. Characteristics of Individuals Who Died in a SODC (n = 32)

Characteristic	Mean
Age	59.2
LOS	23.3
HRST	3.8
ICAP Service Level	32.8
IQ	22.5
	%
Frequency of Psych Dx	50.0
Frequency of ASD	15.6

Question 8. What are the demographics and characteristics of people who transitioned out of a SODC to receive short-term therapy with the expectation to return to a SODC?

A total of five people moved from a SODC to a short-term nursing home to receive services with the expectation that they would ultimately return to a SODC. Table 15 describes the characteristics of the five individuals who transitioned to a short-term nursing home. The mean age for individuals who transitioned to short-term nursing facilities was 64.2 years and they had an average LOS in the SODC of 26.5 years. These individuals had a mean HRST score of 4.0 out of 6 (meaning they had a high moderate health risk). Additionally, individuals who transitioned to a short-term nursing home generally had low ICAP Service Level scores (mean score of 34.6, the second highest level of support needs) and a mean IQ of 26.4. These numbers show that these individuals have extensive health and other support needs. One of the five individuals (20.0%) had at least one psychiatric diagnosis and none of the five were diagnosed with autism.

Table 15. Characteristics of Individuals who Transitioned to Short-Term Nursing Facilities (n = 5)

Characteristic	Mean
Age (years)	64.2
LOS (years)	26.5
HRST	4.0
ICAP Service Level	34.6
IQ	26.4
	n (%)
Frequency of Psych Dx	1 (20.0)
Frequency of ASD	0 (0.0)

Conclusion

This study sought to answer eight questions, discussed in detail throughout the report. A summary of the results that relate to each question is presented in this section.

Answers to Evaluation/Research Questions

Question 1. How many transitions occurred out of SODCs?

- There were 84 live transitions out of SODCs in this timeframe representing 82 people, as two people transitioned twice.
- Together, Shapiro, Choate, and Kiley (n = 70 transitions) accounted for over 80% of the total live transitions out of SODCs.

Question 2. What are the demographics and characteristics of those who transitioned out of SODCs?

- The average age of the 82 people who transitioned out of SODCs (live transitions) was 47.3 years of age, and the majority (73.2%) were male. Slightly more than half (52.4%) of people had family members as their guardian, while 28.0% had a public guardian, and 17.1% were their own guardian. On average, people had lived in the SODC for 14.5 years, ranging from a few weeks to over 53 years. Most people (69.5%) were White.
- Over two-thirds (70.7%) of people who transitioned had at least one psychiatric diagnosis. The most common psychiatric diagnoses were mood (32.9%), psychotic (14.6%), and anxiety (14.6%) disorders. In addition to psychiatric diagnoses, 19.5% of people were diagnosed with ASD and 3.7% were diagnosed with PDD.
- People had varying levels of ID. The largest percentage of individuals had mild ID (31.7%) followed by profound ID (28.0%). People who transitioned had an average ICAP Service Level score of 54.4, putting them in service level 3 (out of 5), which indicates need for “regular personal care and/or close supervision.” They also had a mean HRST level of 2.6 (between low and moderate risk) and about a third (30.5%) had high health risks (≥ 4 HRST score).
- Together, these characteristics indicate that people who transitioned had a variety of disability and psychiatric diagnoses along with personal care and health needs. It is not possible for the evaluation team to assess whether these demographic characteristics differed from the population of people remaining in SODCs.

Question 3. To what type of residential setting did individuals transition? (n = 84 transitions)

- Of the 84 live transitions, the greatest percentage (26.2%) went to SNFs followed by CILAs (25.0%). Approximately 17.9% of transitions went to family settings, followed by 9.5% to jail; 6.0% went to another SODC, another 6.0% went to an ICF/DD, and 2.4% went to a MHC. The remaining 7.1% transitioned to other settings.
- Half of transitions from Shapiro went to CILAs.

Question 4. To what extent did individuals remain in their post-transition setting?

- SODC staff follow-up with people who have transitioned for 12 months after their transition; because of those who transitioned more than a year ago, of the 84 transitions, 19.1% have an unknown or missing current status. 42.9% of transitions had a continuous placement, meaning that they were still in the original transition setting. 22.6% returned to a SODC, and 15.5% died following their transition out of a SODC.
- Of the 21 transitions that went to a CILA and who had a current status, 85.7% remained in the same setting and with the same service provider (continuous placement) and 14.3% returned to a SODC.
- Of people who originally transitioned to and remained in a CILA (n = 18), they were middle-aged (46.1 years on average), had an average HRST score of 2.7 (low to moderate risk), had an average IQ of 31.7, and had an average ICAP Service Level score of 57.0 (Level 3 – regular personal care and/or close supervision).

Question 5. Why did people return to a SODC and did they receive technical assistance (TA)?

- Of the 79 transitions from a SODC to a non-SODC setting, 17 (21.5%) ultimately returned to a SODC. The main reason for return was behavioral (41.2%), followed by short-term therapy (29.4%), medical (17.6%), and other (11.8%).
- TA was provided to all seven returns for a behavioral reason (behavioral TA). TA was not provided to any of those returning because of a medical reason or short-term therapy (n = 8). One of the two that returned for another reason received medical TA while the other did not receive any TA.

Question 6. How do the demographics and characteristics of people who transitioned compare across residential settings?

- Of the 82 people who transitioned out of SODCs, the youngest individuals were those who went to a MHC (mean age = 26.5 years) and those who went to jail (mean age = 33.5 years). People who had been in SODCs the longest generally transferred to other institutional settings including ICF/DDs and SNFs.

- Those transitioning to jail, a MHC, or a family setting had lower health risks than other transition settings. People who went to jail had the highest ICAP service level scores indicating the lowest level of support need. People transitioning to ICF/DDs and SNFs had the lowest percentage of psychiatric diagnosis.

Question 7. What are the demographics and characteristics of people who died in a SODC?

- A total of 32 people died at a SODC. People who died had a mean age of 59.2 years, a mean HRST of 3.8 (moderate to high moderate health risk), and had been in the SODC for an average of 23.3 years. They also had an average ICAP Service Level score of 32.8, a score which represents the second most extensive level of support needs.
- 50.0% had at least one psychiatric disorder and 15.6% had an ASD diagnosis.

Question 8. What are the demographics and 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 to receive services with the expectation that they would ultimately return to a SODC.
- These individuals were on average 64.2 years of age with an average LOS in a SODC of 26.5 years. Additionally, they had a mean HRST score of 4.0 indicating a high moderate health risk and a mean ICAP Service Level score of 34.6 which indicates the second highest level of support needs. Their mean IQ was 26.4.
- These individuals had significant health and personal support needs.

In August 2017, a rate study was initiated by DHS-DDD in response to Judge Sharon Johnson Coleman who declared Illinois out of compliance with the Ligas Consent Decree. More specifically, the judge cited low quality of services primarily as a result of low wages for direct support professionals. As a step toward coming into compliance with the Ligas Consent Decree, an external consultant, Guidehouse (formerly Navigant) was hired. The report was completed in the fall of 2020 and included key recommendations. The FY2022 budget for DHS-DDD included an additional $170 million (partly through the American Rescue Plan), the highest-ever investment in the DD system in Illinois. DHS-DDD plans to use this money to support the Ligas Consent Decree and permanently implement some of the Guidehouse rate study recommendations.

This data also supports the need for policies and programs, including continuing and expanding initiatives such as the Short-Term Stabilization Homes and Support Service Teams, in Illinois to support people with both ID and a psychiatric diagnosis living in non-institutional settings.

Additional research should be completed to better understand the issues around transitions from SODCs. In particular, it is not possible to ascertain from the current data why some transitions are successful and others are not. In-depth qualitative interviews with people who have transitioned could shed more light on this topic.

Illinois would also benefit from research on the full SODC population. One cannot tell from the current report whether the people who were chosen/wanted to transition had different characteristics from those who remained in SODCs. It may be that those who transitioned had lower health risks, were younger, or of different demographics (race, gender, etc.), but without comparable data from the entire SODC census, we cannot make those comparisons. Including this data in the next evaluation would add to the usefulness of the results.

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