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

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Table of Contents

Table of Tables and Figures

Acronyms

ASD: Autism spectrum disorder

CILA: Community-integrated living arrangement

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

DSP: Direct support professional

HRST: Health Risk Screening Tool

ICAP: Inventory for Client and Agency Planning

ICF/DD: Intermediate care facility for developmental disabilities

I-CILA: Intermittent community-integrated living arrangement

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, 2016 – June 30, 2022. Data were collected and analyzed to determine characteristics of and outcomes for persons 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), from July 1, 2016 through June 30, 2020 (Crabb et al., 2021), and from July 1, 2020 through June 30, 2021 (Crabb, Hsieh, et al., 2022) 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 2023.

Findings

Question 1. How many individuals transitioned out of Illinois SODCs?

- There were 527 live transitions out of SODCs in this timeframe. The number of transitions was highest in FY22 (101) and lowest in FY17 (78).
- The 527 live transitions represented 483 people including 35 people who transitioned twice, three who transitioned three times, and one person who transitioned four times.
- There were 192 deaths either within the SODC (146) or in their post-transition setting (46).
- A total of 35 people (representing 41 transitions) moved from a SODC to a short-term nursing home to receive services with the expectation that they would ultimately return to a SODC.

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

- The average age of people who transitioned out of SODCs (live transitions) was 45.9 years of age and the majority (74.1%) were male. The average age significantly decreased from FY17 (50.2) to FY20 (37.2) and then significantly increased from FY20 (37.2) to FY22 (47.8). Slightly more than half of people who transitioned had family members as their guardian (51.6%) while 26.7% had a public guardian. On average, people who transitioned had lived in the SODC for 13.5 years, ranging from several days to over 62 years. Most people who transitioned were White (67.1%), though this percentage decreased from FY18 to FY20 (from 77.0% to 58.2%, respectively) and then increased again in FY21.
- Almost two-thirds (64.4%) of people who transitioned had at least one psychiatric diagnosis. The percentage of people transitioning with a psychiatric diagnosis increased from FY17 to FY22 (from 48.6% to 69.7%) and indicated a statistically significant ($p = .005$) change across the six fiscal years.

- The most common psychiatric diagnoses were mood disorder (29.2%) and psychotic disorder (21.7%). There was a significant change across fiscal years for anxiety and childhood disorders. In addition to psychiatric diagnoses, 14.7% of people who transitioned were diagnosed with autism spectrum disorder (ASD) and 3.1% were diagnosed with pervasive developmental disorder (PDD). ASD diagnosis significantly changed across the six fiscal years: in FY17 only three individuals (4.2%) had an ASD while that percentage rose to 19.2% in FY22.
- People who transitioned had varying levels of intellectual disability (ID). One third had mild ID (34.6%). People who transitioned had an average Inventory for Client and Agency Planning (ICAP) Service Level score of 52.4 putting them in service level 3 (out of 5), which indicates that a person needs "regular personal care and/or close supervision." They also had a mean Health Risk Screening Tool (HRST) level of 2.7 (between low and moderate risk) and over a quarter (30.7%) scored in the high-risk levels (≥ 4 HRST score). Together, these data indicate that people who transitioned had a variety of disability and mental health diagnoses along with personal care and health needs.

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

- Of the 527 live transitions, slightly less than a third (30.7%) went to CILAs, or community-integrated living arrangements (both intermittent CILA, or I-CILA, and 24-hour CILA), 26.2% went to skilled nursing facilities (SNFs), 10.4% went to family settings, 9.1% went to another SODC, 8.9% went to jail, 4.6% went to an intermediate care facility for developmental disabilities (ICF/DD), 4.4% went to a state-operated mental health center (MHC), and 5.7% went to another setting.
- The percentage of transitions to CILAs peaked in FY19 (37.0%). The percentage of transitions to an ICF/DD decreased across the years, with no transitions to an ICF/DD in FY22. Transitions to SNFs dropped in FY20 (from 24.4% in FY17 to 9.4% in FY20), then increased again in FY21, and peaked in FY22 (38.6%).
- The percentage of transitions to other SODCs (9.0% vs.18.8%) and family homes (7.7% vs. 16.5%) increased two-fold from FY17 to FY20.

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; 15.9% had a current status of unknown (largely because of those who transitioned more than a year ago), 42.7% maintained a continuous placement in their new setting following that transition, and 21.6% returned to a SODC; 15.9% went to a MHC and 14.6% died post-transition.
- Of the 160 transitions that went to a CILA and who had a current status, nearly three-quarters (73.1%) remained in the same setting and with the same service provider (continuous placement), while 1.3% remained with the same provider but in a different residence in the community, and 5.6% remained in the community but in a different resident and with another provider. Only 1.9% of people who transitioned to a CILA died, 0.6% went to a MHC and 17.5% returned to a SODC.
- Individuals who transitioned to a CILA (either 24-hour or I-CILA) and remained in the community (continuous placement, or either with the same community provider or a new

community provider) were middled-aged (42.1 years on average), had low to moderate health risk, had a mean IQ of 45.5, and had an average ICAP Service Level score of 61.0 (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 479 transitions from a SODC to a non-SODC setting, 96 returned to a SODC (20.0%). The main reason for return (for those that were not missing a return reason, n = 94) was behavioral (36.2%), followed by other (24.5%), short-term therapy (21.3%), and medical (18.1%).
- Behavioral technical assistance (TA) was provided to 85.3% of those returning for a behavioral reason (behavioral TA). TA was provided to one person (out of 17, 5.9%) that returned for a medical reason (behavioral TA). Of those returning for another reason or for short-term therapy (n = 43), two (4.7%) received TA (one received medical TA and one received behavioral TA).
- Of the returns to a SODC from a CILA, all did so because of a behavioral reason.

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

- Those transitioning to community settings (CILA and family settings), were generally younger (CILA: 41.3 mean age and family: 36.1 mean age) compared to ICF/DDs and SNFs (ICF/DD: 60.3 mean age and SNF: 63.7 mean age).
- People in community settings (CILA and family settings) had lower health risks, especially compared to those in institutional settings like ICF/DDs and SNFs. 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.

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

- A total of 192 people died; either at a SODC (146) or after they transitioned out of a SODC (46). Of the 46 who died post-transition, 13 were missing their post-transition setting (28.2%) and 33 died in another setting (71.7%).
- People who died at a SODC had a mean age of 62.7 years, a mean HRST of 4.0 (high moderate health risk and had been in the SODC for an average of 24.7 years. They also had an average ICAP Service Level score of 30.7, a score within Level 2 which represents the second most extensive support needs. 44.5% had at least one psychiatric disorder and 11.6% had an ASD diagnosis.
- Individuals who died in an “Other” setting had a slightly lower average IQ than those who died in SODCs but had a slightly higher average ICAP Service Level score, indicating they needed less supports. Those who died who were missing a post-transition setting were the youngest, had been in SODCs the longest prior to their transition out, had the highest ICAP

Service Level score (less supports needed), and had the highest average IQ compared to both those who died in SODCs and other settings.

Question 8. 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 (representing 41 transitions) 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 60.0 years of age with an average length of stay (LOS) in a SODC of 20.5 years. Additionally, they had a mean HRST score of 4.2 out of 6 indicating a high moderate to high health risk. Their mean ICAP Service Level score was 28.6 which indicates the highest level of support needs and they had a mean IQ of 19.5.
- These individuals had significant health and personal support needs.

Two primary themes emerged from this evaluation. These are explained below.

Themes

- *Demographic changes around the time of the pandemic (FY20):*
  - The average age significantly decreased from FY17 (50.2) to FY20 (37.2) and significantly increased from FY20 (37.2) to FY22 (47.8).
  - Average LOS increased from 13.6 in FY17 to 15.5 in FY22. The LOS was lowest in FY20 (10.0).
  - The highest percentage of individuals having psychiatric diagnoses was in FY20 (72.2%).
  - The percentage of individuals who were not White increased to a high of 41.8% in FY20 but decreased back to 33.3% in FY22.
  - In FY20, 67.1% of those transitioning had a mild or moderate ID, the highest in those two categories combined across all six fiscal years.
  - ICAP Adaptive Domains of Motor Skills and Social/Communication significantly increased between FY17 and FY20.
  - While there was no significant trend across the six fiscal years, three of the five scores increased significantly from FY17 to FY20 (Personal Living and Community Living did not have a significant increase between FY17 and FY20.)
  - The average ICAP Service Level score did decrease significantly between FY20 and FY22 ($p < .001$).
- *People transitioning out have specific, significant, and sometimes increasing support needs:*
  - The percentage of people transitioning with a psychiatric diagnosis increased from FY17 to FY22 (from 48.6% to 69.7%) and indicated a statistically significant ($p = .005$) increase across the six fiscal years.
  - Autism diagnosis significantly increased across the six fiscal years.
  - There was a significant increase across fiscal years for anxiety and childhood disorders.
  - All the individuals who returned to a SODC from a CILA did so for behavioral reasons.

- Compared to those who maintained community placements, individuals who returned had significantly lower ICAP Maladaptive Behavior Domain scores (with the exception of the Asocial score, which was lower for returners, but not significantly).

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. As of June 30, 2019, 109 institutions were open across the United States compared to 376 between 1960 and 2019 (Larson et al., 2023).

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 between FY17 and FY22, 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 2022 (Crabb, Hsieh, et al., 2022). In the spring of 2023, the Illinois Department of Human Services – Division of Developmental Disabilities (DHS-DDD) extended the database to include transitions from July 1, 2021 through June 30, 2022. 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, 2016 – June 30, 2022, are:

1) How many individuals transitioned out of Illinois SODCs?
2) What are the demographics and characteristics of those who transitioned out of SODCs in Illinois?
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 persons who transitioned compare across residential settings?
7) What are the demographics and characteristics of people who died since transitioning from 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, 2016 and June 30, 2022** 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), July 1, 2016 – June 30, 2020 (Crabb et al., 2021), and July 1, 2020 – June 30, 2021 (Crabb, Hsieh, et al., 2022).

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 2023:

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 TA post-transition

Data was coded and then analyzed using SPSS Statistics 28.0 software. This report presents results of that analysis including descriptive information and basic comparisons between transition groups, including comparisons of originating SODCs and by fiscal year.

Results

The results of this evaluation are organized around the eight questions noted in the Introduction to this report. Unless otherwise noted, the time frame for the data below is July 1, 2016 through June 30, 2022. Some tables are broken out by fiscal year.

Question 1. How many transitions occurred out of Illinois SODCs?

A total of 527 live transitions out of the Illinois SODC system occurred during the entire time period. These transitions represented 483 people, as 444 people transitioned only once, 35 people transitioned twice, three people transitioned three times, and one person transitioned four times during the time period. Questions one through six focus on these 527 live transitions representing 483 people, while question seven focuses on transitions from SODCs where the person died in the SODC during this period (146 people) and on people who died in their transition setting following discharge (46 people) from a SODC. Question eight focuses on 35 people (representing 41 transitions) 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.

As shown in Table 1, the number of live transitions out of SODCs increased between FY17 (78) and FY22 (101). FY22 represented the largest percentage of transitions, accounting for 19.2% of the total transitions and FY17 represented the smallest percentage of total transitions (14.8%). The Choate Developmental Center (Choate) accounted for the most transitions over this period (192, 36.4%). The second highest number of transitions were from Governor Samuel H. Shapiro Developmental Center (Shapiro) with 152 (28.8%) transitions. Together, Choate and Shapiro accounted for nearly two thirds (65.2%) of the total transitions from SODCs in Illinois. Ludeman Developmental Center (Ludeman) transitioned 13.5% of the total transitions. The remaining SODCs, including Fox Developmental Center (Fox), Kiley Developmental Center (Kiley), Jack Mabley Developmental Center (Mabley), and Murray Developmental Center (Murray), each accounted for between 1.1% and 12.1% of the total transitions.

Table 1: SODC Transitions by Fiscal Year

SODC	FY17	FY18	FY19	FY20	FY21	FY22	FY17-FY22	% of Total by SODC
Choate	33	30	45	30	25	29	192	**36.4%**
Fox	3	0	0	1	1	1	6	**1.1%**
Kiley	6	8	7	8	19	16	64	**12.1%**
Ludeman	8	14	11	18	9	11	71	**13.5%**
Mabley	0	2	1	4	3	4	14	**2.7%**
Murray	6	3	5	4	1	9	28	**5.3%**
Shapiro	22	30	23	20	26	31	152	**28.8%**
Total	78	87	92	85	84	101	527	
% of Total by FY	**14.8%**	**16.5%**	**17.5%**	**16.1%**	**15.9%**	**19.2%**		

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

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 broken out by fiscal year and also across the entire time period. For the individuals that transitioned multiple times during the time period, only their most recent transition was used to calculate demographics (n = 483). 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 discharge. Of the 483 individuals who transitioned out of the seven Illinois SODCs during the study period, the youngest was 18 years and the oldest was 100. The average age was 45.9 (SD = 17.9) years at the time of transition. A trend analysis indicates a curved trend (p =.01) showing a decrease in age initially followed by an increase across years. The average age significantly decreased from FY17 (50.2) to FY20 (37.2) and then significantly increased from FY20 (37.2) to FY22 (47.8).

Length of Stay (LOS)

People who transitioned out of a SODC during the study period had lived in the SODC for an average of 13.5 years, ranging from several days to over 62 years (SD = 15.8). A trend analysis showed no significant change in LOS across the six years. The average LOS was lowest in FY20 (10.0) and highest in FY22 (15.5).

Gender

Across all six fiscal years, most of the individuals who transitioned out of the SODCs were male (74.1%); the percentage of males was the highest during FY17 (80.6%) and lowest during FY22 (68.7%). There was no significant change in the percentage of males across the six fiscal years.

Race

Across FY17-FY22, most people who transitioned out of SODCs were White (67.1%): this percentage decreased from FY18 to FY20 (from 77.0% to 58.2%, respectively) and then increased again in FY21 to 71.4%. There was no significant change in the percentage of White individuals across the six fiscal years.

Guardianship Status

Slightly more than half of the individuals who transitioned out of SODCs during the study period had family members as their guardians (51.6%). Over a quarter of the 483 individuals that transitioned had a public guardian (129, 26.7%) and about a fifth were their own guardian, or deemed legally competent (98, 20.3%). There was no significant change in the distribution of guardianship type across the six fiscal years.

Table 2: Demographics by Fiscal Year

	FY17 (n = 72)	FY18 (n = 74)	FY19 (n = 82)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 99)	FY17-FY22 (n = 483)
	mean (SD)						
Age	50.2 (17.0)	48.2 (19.6)	44.2 (15.7)	37.2 (15.4)	48.1 (17.4)	47.8 (18.9)	45.9 (17.9)
LOS	13.6 (15.0)	14.3 (16.6)	12.2 (14.5)	10.0 (13.0)	15.1 (17.3)	15.5 (17.4)	13.5 (15.8)
	n (%)						
Gender							
Male	58 (80.6%)	54 (73.0%)	60 (73.2%)	60 (75.9%)	58 (75.3%)	68 (68.7%)	358 (74.1%)
Female	14 (19.4%)	20 (27.0%)	22 (26.8%)	19 (24.1%)	19 (24.7%)	31 (31.3%)	125 (25.9%)
Race							
White	48 (66.7%)	57 (77.0%)	52 (63.4%)	46 (58.2%)	55 (71.4%)	66 (66.7%)	324 (67.1%)
Non-White	24 (33.3%)	17 (23.0%)	30 (36.6%)	33 (41.8%)	22 (28.6%)	33 (33.3%)	159 (32.9%)
Guardianship							
Own	14 (19.4%)	17 (23.0%)	18 (22.0%)	19 (24.1%)	13 (16.9%)	17 (17.2%)	98 (20.3%)
Public	14 (19.4%)	20 (27.0%)	25 (30.5%)	24 (30.4%)	22 (28.6%)	24 (24.2%)	129 (26.7%)
Family	44 (61.1%)	36 (48.6%)	38 (46.3%)	34 (43.0%)	40 (51.9%)	57 (57.6%)	249 (51.6%)
Non-Family	0 (0.0%)	1 (1.4%)	1 (1.2%)	2 (2.5%)	2 (2.6%)	1 (1.0%)	7 (1.4%)

Psychiatric Diagnosis

Figure 1 illustrates the percentages of those transitioning across the entire time frame with a diagnosed psychiatric disorder. Of the 483 individuals who transitioned, 311 people (64.4%) had at least one psychiatric diagnosis. The percentage of people transitioning with a psychiatric diagnosis increased from FY17 to FY22 (from 48.6% to 69.7%) and indicated a statistically significant ($p = .005$) increase across the six fiscal years.

Figure 1: Percentage of Psychiatric Diagnosis of Individuals Transitioning by Fiscal Year

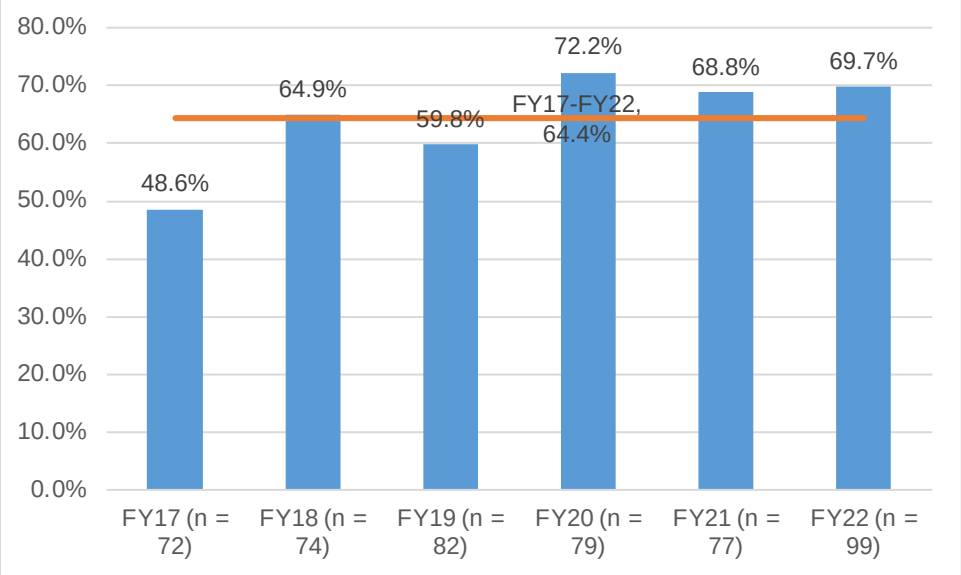


Table 3 describes the number and types of psychiatric diagnoses by fiscal year. Over the course of the six fiscal years, the majority had a psychiatric diagnosis (64.4%); over a third had a single psychiatric diagnosis (35.8%) and 28.6% had two or more psychiatric diagnoses. The most common psychiatric diagnoses were mood disorder (29.2%), psychotic disorder (21.7%), childhood disorders (12.2%), impulse control disorder (10.1%), anxiety disorders (9.9%), and personality disorders (7.0%). There was a significant increase across fiscal years for anxiety and childhood disorders.

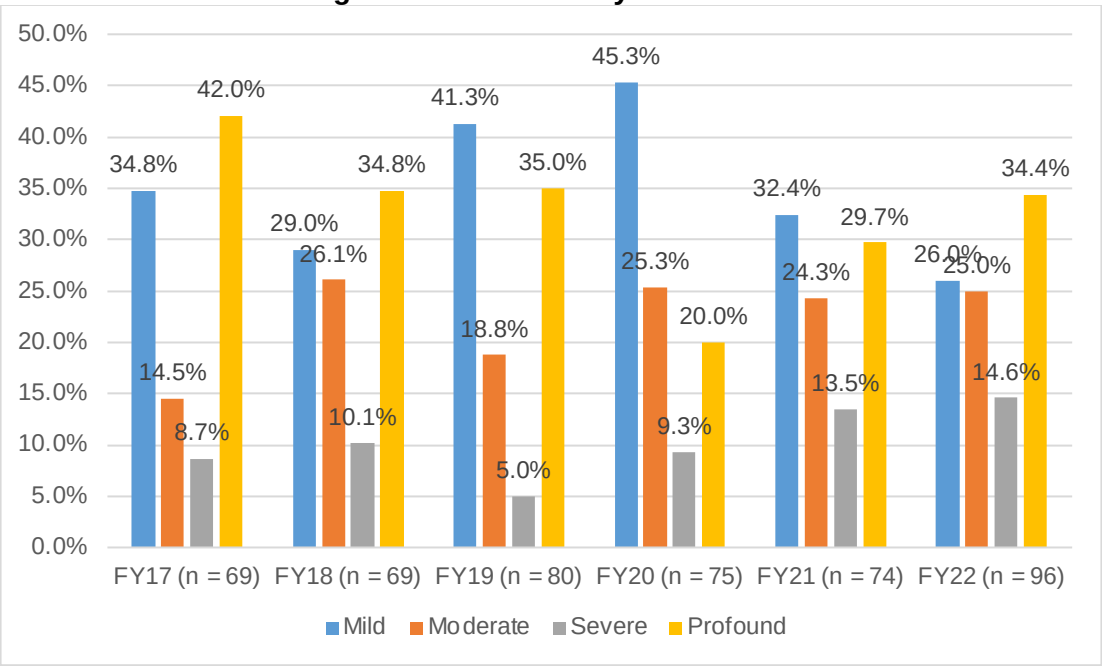
Table 3: Psychiatric Diagnosis by Fiscal Year

	FY17 (n = 72)	FY18 (n = 74)	FY19 (n = 82)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 99)	FY17-FY22 (n = 483)
	n (%)						
Number of psychiatric diagnoses							
0	37 (51.4%)	26 (35.1%)	33 (40.2%)	22 (27.8%)	24 (31.2%)	30 (30.3%)	172 (35.6%)
1	18 (25.0%)	31 (41.9%)	29 (35.4%)	30 (38.0%)	33 (42.9%)	32 (32.3%)	173 (35.8%)
2	11 (15.3%)	13 (17.6%)	11 (13.4%)	19 (24.1%)	12 (15.6%)	23 (23.2%)	89 (18.4%)
3	6 (8.3%)	3 (4.1%)	6 (7.3%)	8 (10.1%)	5 (6.5%)	9 (9.1%)	37 (7.7%)
4	0 (0.0%)	1 (1.4%)	3 (3.7%)	0 (0.0%)	2 (2.6%)	4 (4.0%)	10 (2.1%)
5	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.3%)	1 (1.0%)	2 (0.4%)
Psychiatric diagnosis*							
Psychotic	15 (20.8%)	17 (23.0%)	15 (18.3%)	20 (25.3%)	12 (15.6%)	26 (26.3%)	105 (21.7%)
Impulse	9 (12.5%)	4 (5.4%)	9 (11.0%)	9 (11.4%)	8 (10.4%)	10 (10.1%)	49 (10.1%)
Anxiety	4 (5.6%)	5 (6.8%)	7 (8.5%)	7 (8.9%)	12 (15.6%)	13 (13.1%)	48 (9.9%)
Mood	15 (20.8%)	28 (37.8%)	22 (26.8%)	26 (32.9%)	25 (32.5%)	25 (25.3%)	141 (29.2%)
Sexual	0 (0.0%)	0 (0.0%)	1 (1.2%)	2 (2.5%)	0 (0.0%)	0 (0.0%)	3 (0.6%)
Personality	3 (4.2%)	5 (6.8%)	8 (9.8%)	8 (10.1%)	6 (7.8%)	4 (4.0%)	34 (7.0%)
Childhood	6 (8.3%)	6 (8.1%)	9 (11.0%)	9 (11.4%)	8 (10.4%)	21 (21.2%)	59 (12.2%)
Substance	0 (0.0%)	2 (2.7%)	1 (1.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (0.6%)
Adjustment	1 (1.4%)	0 (0.0%)	1 (1.2%)	1 (1.3%)	0 (0.0%)	2 (2.0%)	5 (1.0%)
Non-Psychotic	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (1.3%)	1 (1.3%)	0 (0.0%)	2 (0.4%)

Level of Intellectual Disability (ID)

Of the 483 individuals who transitioned out of a SODC across the entire time frame, 99.0% (n = 478) had a diagnosis of ID. Figure 2 illustrates the level of ID by fiscal year. One third (34.6%) of those who transitioned during the time period had a mild ID, though the percentage with a mild ID decreased from 45.3% in FY20 to 32.4% in FY21 and then to 26.0% in FY22 (while the percentage with a profound ID increased during this same time period). Profound was the next highest category across the entire study period (32.6%). There was no significant change in the distribution of level of ID by fiscal year.

Figure 2: Level of ID by Fiscal Year



Autism Spectrum Disorder (ASD) Diagnosis

Over the course of six fiscal years, 14.7% of people who transitioned had a diagnosis of autism spectrum disorder (ASD), which includes Asperger's, while 3.1% had pervasive developmental disorder (PDD). Table 4 shows the frequency of these diagnoses by fiscal year. ASD diagnosis significantly increased across the six fiscal years: in FY17, only three individuals (4.2%) had an ASD while that percentage rose to 19.2% in FY22.

Table 4: Frequency of ASD Diagnosis by Fiscal Year

ASD Dx	FY17 (n = 72)	FY18 (n = 74)	FY19 (n = 82)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 99)	FY17-FY22 (n = 483)
	n (%)						
No ASD Dx	66 (91.7%)	62 (83.8%)	68 (82.9%)	63 (79.7%)	59 (76.6%)	79 (79.8%)	397 (82.2%)
ASD	3 (4.2%)	8 (10.8%)	11 (13.4%)	15 (19.0%)	15 (19.5%)	19 (19.2%)	71 (14.7%)
PDD	3 (4.2%)	4 (5.4%)	3 (3.7%)	1 (1.3%)	3 (3.9%)	1 (1.0%)	15 (3.1%)

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

Table 5 shows the average ICAP Adaptive Behavior Domain scores by fiscal year. 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. The lowest ICAP Adaptive Behavior Domain score was in the area of Motor Skills (432.4) while the highest was in the area of Personal Living (469.4). These scores indicate deficits in each area of Adaptive Behavior. A trend analysis indicates no significant trend was found in each adaptive area mean score across

years. While there was no significant trend across the six fiscal years, three of the five scores increased significantly from FY17 to FY20 (Personal Living and Community Living did not have a significant increase between FY17 and FY20.)

Table 5: Mean ICAP Adaptive Behavior Domain Scores by Fiscal Year

Adaptive Area	FY17 (n = 72)	FY18 (n = 72)	FY19 (n = 81)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 97)	FY17-FY22 (n = 478)
Motor Skills	418.1	430.7	433.7	451.3	435.2	425.7	432.4
Social & Communication Skills	439.8	449.0	450.8	466.9	448.9	444.7	450.0
Personal Living	458.7	467.2	470.5	481.2	471.2	467.3	469.4
Community Living	437.5	450.9	452.8	465.3	451.2	444.3	450.3
Broad Independence	437.8	449.6	453.1	466.0	451.7	445.6	450.7

Inventory for Client and Agency Planning (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

Table 6 describes the average, minimum, and maximum ICAP Service Level Scores by fiscal year and for the entire study period. The range of ICAP Service Level Scores during the study period was 1 - 95. The average ICAP Service Level Score for individuals who transitioned was 52.4 (SD = 24.1) which indicates an average need (Level 3) for regular personal care and close supervision. A trend analysis indicates no significant trend was found in the mean ICAP service level score across years. However, the average ICAP Service Level score did decrease significantly ($p < .001$) between FY20 and FY22.

Table 6: ICAP Service Level Scores by Fiscal Year

	FY17 (n = 72)	FY18 (n = 72)	FY19 (n = 81)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 97)	FY17-FY22 (n = 478)
Minimum	9	13	5	2	12	1	1
Mean	50.1	52.8	54.4	59.5	54.3	45.0	52.4
Maximum	95	94	88	92	90	92	95

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

Table 7 shows the average ICAP Maladaptive Behavior Domain scores by fiscal year. Maladaptive Behavior Domain scores range from -41 and below to +10. Overall, the Maladaptive Behavior General Score was the lowest (-11.5) while the Internalized score was the highest (-6.7). The General Maladaptive Behavior Score is the lowest and represents a marginally serious maladaptive behavior. The remaining scores are all within the normal limits. No significant trend across the six fiscal years in the means of internalized and asocial maladaptive scores were detected. There was a significant a U-shaped trend in externalized maladaptive behavior (p =.008) and general maladaptive behavior (p = .02). The lower mean externalized maladaptive score represents an increased frequency/severity of problem behaviors of being hurtful to others, destructive to property, or engaging in disruptive behavior.

Table 7: Mean ICAP Maladaptive Behavior Domain Scores by Fiscal Year

Maladaptive Area	FY17 (n = 72)	FY18 (n = 72)	FY19 (n = 81)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 97)	FY17-FY22 (n = 478)
Internalized	-5.3	-8.3	-5.8	-7.4	-6.7	-6.6	-6.7
Asocial	-8.8	-10.6	-10.9	-11.0	-8.8	-8.8	-9.8
Externalized	-4.6	-8.5	-8.0	-9.2	-9.5	-8.6	-8.1
General	-8.9	-12.5	-11.4	-12.6	-11.6	-11.6	-11.5

Health Risk Screening Tool (HRST)

The Health Risk Screening Tool (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, as indicated in the table below.

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

Table 8 shows the percentage of people with high HRST scores (≥ 4) and the mean HRST score for each fiscal year and for the entire study period. HRST scores for individuals who transitioned during the study period range from level 1 to level 6 and the average HRST score was 2.7 (SD = 1.6), which is in the low to moderate risk level. The percentage of people in the high to highest HRST score group was highest in FY17 (38.5%) with a mean HRST of 3.0 (moderate risk level) and lowest in FY20 (19.0%) with a mean HRST of 2.3 (low to moderate risk level). A trend analysis indicates no significant trend was found in the mean HRST score across years.

Table 8: HRST Health Risk Levels

HRST	FY17 (n = 65)	FY18 (n = 64)	FY19 (n = 79)	FY20 (n = 79)	FY21 (n = 77)	FY22 (n = 98)	FY17-FY22 (n = 462)
% High HRST (≥ 4)	38.5%	37.5%	27.8%	19.0%	31.2%	32.7%	30.7%
Mean HRST	3.0	3.0	2.5	2.3	2.7	2.8	2.7

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

Table 9 describes the percentage of transitions (n = 527) from each SODC to various types of residential settings between July 1, 2016 and June 30, 2022. Though post-transition settings varied by SODC, transitions out of a SODC and into a community-integrated living arrangement (CILA), either 24-hour or an intermittent-CILA (I-CILA) setting, made up over a quarter (30.7%) of the 527 transitions during the entire time period. The second most common post-transition setting was a skilled nursing facility (SNF), which made up 26.2% of the transitions during the time period. Approximately 10.4% went to family settings, 9.1% of transitions went to another SODC, followed by 8.9% of transitions to jail; 4.6% went to an intermediate care facility for developmental disabilities (ICF/DD) and 4.4% went to a state-operated mental health center (MHC). The remaining 5.7% transitioned to other settings. Murray had the highest percent of transitions that went to CILAs (42.9%) while Fox had no transitions to CILAs, though Fox only had six transitions out during the study period.

Table 9: Discharge Setting by SODC Discharged From

Setting	Choate (n = 192)	Fox (n = 6)	Kiley (n = 64)	Ludeman (n = 71)	Mabley (n = 14)	Murray (n = 28)	Shapiro (n = 152)	Total (n = 527)
CILA	33.9%	0.0%	31.3%	21.1%	35.7%	42.9%	29.6%	30.7%
Jail	24.5%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	8.9%
Family	14.1%	0.0%	7.8%	4.2%	21.4%	25.0%	6.6%	10.4%
ICF/DD	3.1%	50.0%	0.0%	8.5%	14.3%	3.6%	3.9%	4.6%
Other SODC	8.3%	0.0%	0.0%	23.9%	0.0%	14.3%	7.2%	9.1%
MHC	8.3%	0.0%	3.1%	7.0%	0.0%	0.0%	0.0%	4.4%
SNF	0.5%	16.7%	48.4%	32.4%	0.0%	14.3%	51.3%	26.2%
Other	7.3%	33.3%	9.4%	2.8%	28.6%	0.0%	1.3%	5.7%

Table 10 illustrates the transition settings by fiscal year. The percentage of transitions to CILAs peaked in FY19 (37.0%). The percentage of transitions to an ICF/DD decreased across the years, with no transitions to an ICF/DD in FY22. Transitions to SNFs dropped in FY20 (from 24.4% in FY17 to 9.4% in FY20) then increased again in FY21 and peaked in FY22 (38.6%). The percentage of transitions to other SODCs (9.0% vs.18.8%) and family homes (7.7% vs. 16.5%) increased two-fold from FY17 to FY20.

Table 10: Discharge Settings by Fiscal Year

Setting	FY17 (n = 78)	FY18 (n = 87)	FY19 (n = 92)	FY20 (n = 85)	FY21 (n = 84)	FY22 (n = 101)	FY17-FY22 (n = 527)
CILA	28.2%	29.9%	37.0%	30.6%	25.0%	32.7%	30.7%
Jail	10.3%	9.2%	6.5%	10.6%	9.5%	7.9%	8.9%
Family	7.7%	4.6%	6.5%	16.5%	17.9%	9.9%	10.4%
ICF/DD	10.3%	6.9%	2.2%	3.5%	6.0%	0.0%	4.6%
Other SODC	9.0%	4.6%	12.0%	18.8%	6.0%	5.0%	9.1%
MHC	1.3%	8.0%	6.5%	4.7%	2.4%	3.0%	4.4%
SNF	24.4%	32.2%	23.9%	9.4%	26.2%	38.6%	26.2%
Other	9.0%	4.6%	5.4%	5.9%	7.1%	3.0%	5.7%

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

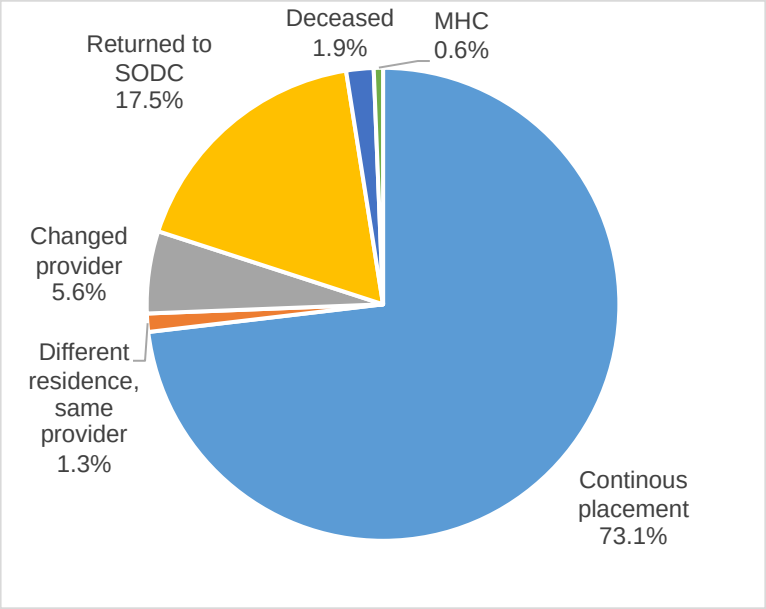
Regulations only require the Department of Human Services follow individuals for one year after they transitioned. Because data for this report covers July 1, 2016 – June 30, 2022, the SODCs from which individuals transitioned were not required to track the current living situation of many of these individuals at the time data was provided (March 2023). As a result, the current status of 15.9% of the transitions during this period are unknown and 0.9% are missing. 42.7% maintained a continuous placement in their new setting following that transition and 21.6% returned to a SODC; 14.6% died post-transition and 0.8% went to a MHC. See Table 11.

Table 11: Current Status of Transitioned Individuals by Fiscal Year

Current Status	FY17 (n = 78)	FY18 (n = 87)	FY19 (n = 92)	FY20 (n = 85)	FY21 (n = 84)	FY22 (n = 101)	FY17-FY22 (n = 527)
Continuous placement	50.0%	41.4%	44.6%	43.5%	42.9%	35.6%	42.7%
Different residence, same provider	1.3%	0.0%	1.1%	1.2%	0.0%	1.0%	0.8%
Changed provider	1.3%	1.1%	2.2%	8.2%	0.0%	3.0%	2.7%
Returned to SODC	10.3%	33.3%	31.5%	11.8%	22.6%	18.8%	21.6%
Deceased	24.4%	11.5%	9.8%	10.6%	15.5%	16.8%	14.6%
MHC	0.0%	0.0%	2.2%	1.2%	0.0%	1.0%	0.8%
Unknown	11.5%	12.6%	8.7%	22.4%	16.7%	22.8%	15.9%
Missing	1.3%	0.0%	0.0%	1.2%	2.4%	1.0%	0.9%

Of the 160 transitions from a SODC to a CILA (24-hour or I-CILA) from July 1, 2016 through June 30, 2022 (Figure 3) with a current status, nearly three-quarters (73.1%) remained at the same home and with the same service provider. About a fifth of those discharged to CILAs returned to a SODC (17.5%).

Figure 3: Current Status of Transitions from a SODC to a CILA (n = 160)



Individuals who transitioned to a CILA (either 24-hour or I-CILA) and remained in the community (continuous placement, or either with the same community provider or a new community provider) had a mean age of 42.1 years, mean HRST score of 2.1 (low to moderate health risk), mean IQ of 45.5, and a mean ICAP Service Level score of 61.0, indicating an average need (Level 3) for regular personal care and close supervision, see Table 12.

Table 12: Characteristics of Transitions to and Remained in the Community by Fiscal Year

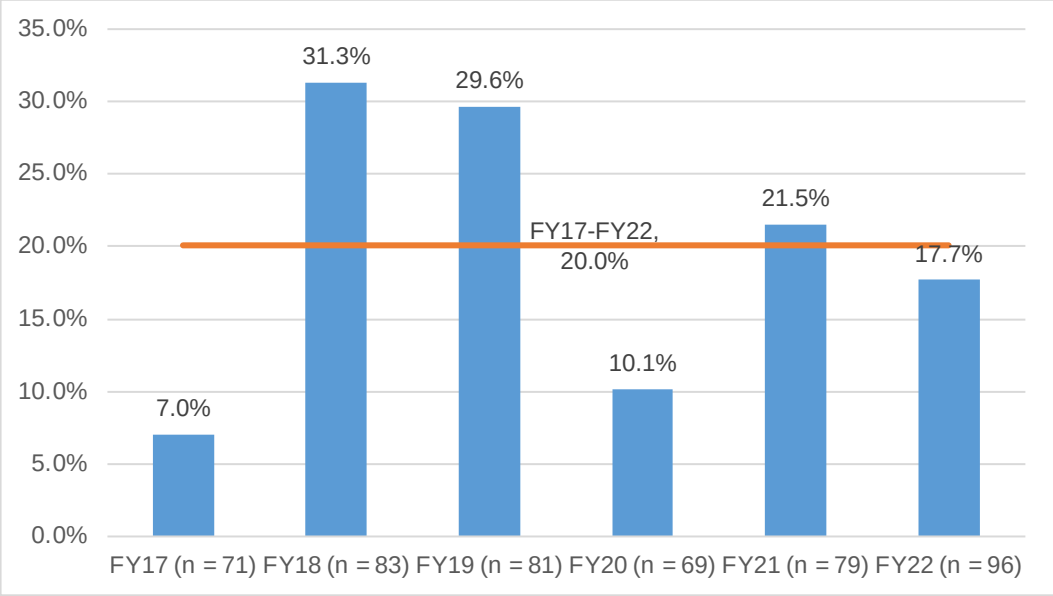
Characteristic *	FY17 (n = 18)	FY18 (n = 18)	FY19 (n = 26)	FY20 (n = 22)	FY21 (n = 18)	FY22 (n = 26)	FY17-FY22 (n = 128)
Age (years)	49.0	41.0	40.9	36.4	46.1	41.2	42.1
HRST	1.8	1.8	2.0	1.9	2.7	2.1	2.1
IQ	52.7	43.5	43.7	52.3	31.7	47.9	45.5
ICAP Service Level	64.6	53.0	63.9	65.9	57.0	59.9	61.0

*Due to missing data, the sample size may be lower for some variables.

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

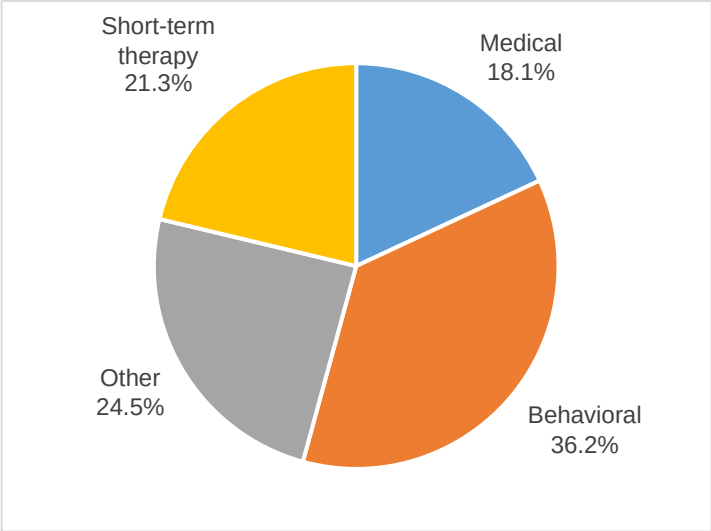
Between July 1, 2016 and June 30, 2022, of the 479 transitions from a SODC to a non-SODC setting, 96 ultimately returned to a SODC (20.0%). The percentage of those returning to a SODC rose sharply from FY17 to FY18 (7.0% to 31.3%) and then fell again in FY20 to 10.1% before increasing again in FY21 (Figure 4).

Figure 4: Frequency of Return to a SODC from a Non-SODC Post-Transition Placement (n = 479)



The discharge summary sheet had the following response options for the reason for a return to a SODC: medical, behavioral, discharged for short-term therapy which concluded, or other. Figure 5 illustrates the reasons for return to a SODC after discharge. Of the 94 returns to a SODC where the return reason was not missing, the main reason for return was behavioral (36.2%), followed by other (24.5%), short-term therapy (21.3%), and medical (18.1%), see Figure 5.

Figure 5: Reasons for Return to a SODC from a Non-SODC Post-Transition Setting (n = 94)



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 13 shows the number of transitions that returned to a SODC, along with the percent of those returns receiving TA. Choate (32) and Shapiro (26) had the highest number of returns with 53.1% of those receiving TA at Choate and 34.6% receiving TA at Shapiro. Kiley had 19 returns, three of which received TA (15.8%). Ludeman had 15 returns and two were provided with TA (13.3%). Of the three returns to Murray, one received TA. Fox had no returns and the single return to Mabley did not receive TA.

Table 13: Receipt of TA for SODC Returners by Center

SODC	Number Receiving TA	Number of Returns	Percent Receiving TA
Choate	17	32	53.1%
Fox	0	0	0.0%
Kiley	3	19	15.8%
Ludeman	2	15	13.3%
Mabley	0	1	0.0%
Murray	1	3	33.3%
Shapiro	9	26	34.6%
Total	**32**	**96**	**33.3%**

Figure 6 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 17 transitions back to a SODC because of medical reasons, only one received TA (behavioral TA, 5.9%). Conversely, for those who returned to a SODC because of behavioral reasons, 85.3% received behavioral TA and one (2.9%) received medical and behavioral TA. Of the remaining 43 transitions (23 for other reasons and 20 due to a short-term therapy return), two received TA (4.7%).

Figure 6: Reason for Return to SODC from a Non-SODC Post-Transition Setting by TA Received (n = 94)

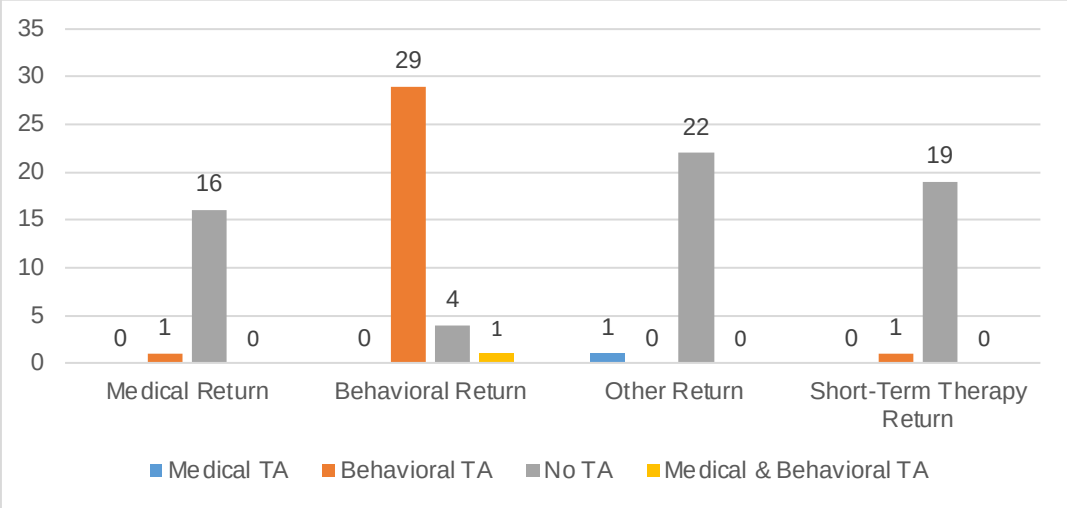


Table 14 compares the reason (medical, behavioral, other, and short-term therapy), for a return to a SODC by the setting from which they returned to the SODC. Those that returned from a CILA did so for behavioral reasons (100%). Of the 42 that returned to a SODC from a SNF and had a reason for return, 16 did so for medical reasons (38.1%), 12 did so for short-term therapy (28.6%), and the other 14 did so for another reason (33.3%).

Table 14: Reason for Return to a SODC by Non-SODC Post-Transition Placement (n = 94)

Reason for Return	24-Hour CILA (n = 28)	Jail (n = 3)	Family (n = 4)	ICF/DD (n = 2)	MHC (n = 11)	SNF (n = 42)	Other (n = 4)
Medical	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	16 (38.1%)	1 (25.0%)
Behavioral	28 (100.0%)	0 (0.0%)	4 (100.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Other	0 (0.0%)	3 (100.0%)	0 (0.0%)	0 (0.0%)	4 (36.4%)	14 (33.3%)	2 (50.0%)
Short-term therapy	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	7 (63.6%)	12 (28.6%)	1 (25.0%)

Compared to those who maintained community placements, individuals who returned had significantly lower ICAP Maladaptive Behavior scores (with the exception of the Asocial score, which was lower for returners, but not significantly).

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

For those individuals that transitioned multiple times 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 jail (mean age = 28.3) and those who went to a MHC (mean age = 28.4). Those who transitioned to community settings, including CILAs and family settings, were also generally younger (41.3 mean age for CILAs and 36.1 mean age for family settings) than other transition settings, such as SNFs and ICF/DDs. The oldest individuals transferred to SNFs (mean age = 63.7). People who had been in SODCs the longest generally transferred to other institutional settings including ICF/DDs and SNFs. Those in community settings also had lower health risks than other settings, specifically lower than institutional settings including ICF/DDs and SNFs. In fact, those that transitioned to SNFs and ICF/DDs had the highest health risks, lowest average ICAP Service Level scores (indicating greater support need), and the lowest IQs. People who went to jail had the highest ICAP service level scores indicating the lowest level of support need. People transitioning to another SODCs and those transitioning to MHCs had the highest percentage of having at least one psychiatric diagnosis. People transitioning out of SODCs and into ICF/DDs had the highest percentage of an ASD diagnosis (25.0%).

Table 15: Characteristics of Transitions by Post-Transition Residential Setting

Characteristic*	CILA (n = 153)	Jail (n = 44)	Family (n = 53)	ICF/DD (n = 24)	Other SODC (n = 42)	MHC (n = 13)	SNF (n = 125)	Other (n = 29)
	mean							
Age	41.3	28.3	36.1	60.3	38.0	28.4	63.7	45.8
LOS	9.5	0.6	7.3	24.9	7.2	3.1	26.3	15.0
HRST	2.1	1.0	2.0	3.5	2.5	1.7	4.1	2.8
ICAP Service Level	60.6	77.6	59.1	34.5	51.8	66.3	33.3	51.9
IQ	45.7	63.9	47.7	21.9	45.1	59.0	19.8	37.1
	%							
Psych Dx	74.5%	52.3%	73.6%	41.7%	81.0%	92.3%	50.4%	55.2%
ASD Dx	20.9%	11.4%	17.0%	25.0%	23.8%	15.4%	12.0%	13.8%

*Due to missing data, the sample size may be lower for some variables.

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

A total of 192 people died either at a SODC or after they had transitioned out of a SODC from July 1, 2016 to June 30, 2022. 146 people died in a SODC and 46 died elsewhere (13 missing a location and 33 died in an “other” location). Table 16 compares demographic characteristics of individuals who died across the settings. Individuals that died in a SODC were older (mean age = 62.7 years), had a lower average ICAP service level score (30.7, indicating a higher level of support needed), and had a higher average health risk (mean HRST score = 4.0), compared to those who died in other settings or whose post-transition setting was missing. The average LOS prior to death in a SODC was highest in missing post-transition settings (27.6 years). Nearly half of the individuals who died had at least one psychiatric diagnosis. Overall, 9.9% of people who died had ASD, which was higher for those who died in SODCs (11.6%) versus those who died in other settings (3.0%) or were missing their post-transition setting (7.7%).

Table 16: Characteristics of Individuals who Died Across Settings (n = 192)

Characteristic*	Missing (n = 13)	SODC (n = 146)	Other (n = 33)	Total (n = 192)
	mean			
Age	58.6	62.7	59.7	61.9
LOS	27.6	24.7	25.8	25.1
HRST	3.5	4.0	3.5	3.9
ICAP Service Level	36.2	30.7	32.3	31.3
IQ	23.2	20.8	18.6	20.6
	%			
Frequency of Psych Dx	46.2%	44.5%	54.5%	46.4%
Frequency of ASD	7.7%	11.6%	3.0%	9.9%

*Due to missing data, the sample size may be lower for some variables.

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 35 people (representing 41 transitions) moved from a SODC to a short-term nursing home to receive services with the expectation that they would ultimately return to a SODC between July 1, 2016 and June 30, 2022.

As there was one individual who transitioned four times and three individuals who transitioned twice out of a SODC and to a short-term nursing home twice during the time period, the data below includes only their most recent discharge. Table 17 describes the characteristics of the 35 individuals who transitioned to a short-term nursing home across the entire study period. The mean age for individuals who transitioned to short-term nursing facilities was 60.0 years and they had an average LOS in the SODC of 20.5 years. These individuals had a mean HRST score of 4.2 out of 6 (meaning they had a high moderate to high health risk). Additionally, individuals who transitioned to a short-term nursing home generally had low ICAP Service Level scores (mean score of 17.9, the highest level of support needs) and a mean IQ of 19.5. These numbers show that these individuals have extensive health and other support needs. 15 individuals (42.9%) had at least one psychiatric diagnosis and five (14.3%) were diagnosed with ASD.

Table 17: Characteristics of Individuals who Transitioned to Short-Term Nursing Facilities (n = 35)

Characteristic	
	mean (SD)
Age	60.0 (9.3)
LOS	20.5 (17.1)
HRST	4.2 (1.7)
ICAP Service Level	28.6 (17.9)
IQ	19.5 (16.1)
	n (%)
Frequency of Psych Dx	15 (42.9%)
Frequency of ASD	5 (14.3%)

Conclusion

Two primary themes emerged from this evaluation. These are explained below.

Themes

- *Demographic changes around the time of the pandemic (FY20):*
  - The average age significantly decreased from FY17 (50.2) to FY20 (37.2) and significantly increased from FY20 (37.2) to FY22 (47.8).
  - Average LOS increased from 13.6 in FY17 to 15.5 in FY22. The LOS was lowest in FY20 (10.0).
  - The highest percentage of having psychiatric diagnoses was in FY20 (72.2%).
  - The percentage of individuals who were not White increased to a high of 41.8% in FY20 but decreased back to 33.3% in FY22.
  - In FY20, 67.1% of those transitioning had a mild or moderate ID, the highest in those two categories combined across all six fiscal years.
  - ICAP Adaptive Domains of Motor Skills and Social/Communication significantly increased between FY17 and FY20.
  - While there was no significant trend across the six fiscal years, three of the five scores increased significantly from FY17 to FY20 (Personal Living and Community Living did not have a significant increase between FY17 and FY20.)
  - The average ICAP Service Level score did decrease significantly between FY20 and FY22.
- *People transitioning out have specific, significant, and sometimes increasing support needs:*
  - The percentage of people transitioning with a psychiatric diagnosis increased from FY17 to FY22 (from 48.6% to 69.7%) and indicated a statistically significant ($p = .005$) increase across the six fiscal years.
  - Autism diagnosis significantly increased across the six fiscal years.
  - There was a significant increase across fiscal years for anxiety and childhood disorders.
  - All the individuals who returned to a SODC from a CILA did so for behavioral reasons.

- Compared to those who maintained community placements, individuals who returned had significantly lower ICAP Maladaptive Behavior Domain scores (with the exception of the Asocial score, which was lower for returners, but not significantly).

Interpreting these themes without further research should be done with caution. The themes suggest that more individuals with more significant behavioral support needs are difficult for community providers to support, which is consistent with previous anecdotal evidence (Crabb, Heller, et al., 2022). In FY22, DDD contracted with UIC's IDHD to create a report assessing the Illinois DD system's capacity to serve individuals with significant or specific support needs. The intent of this work was to understand who is offering these supports in the system, identify providers who could serve as models on specific support needs, and identify ways to expand the capacity of the State to provide these supports to people with IDD. The report included a number of recommendations for DDD to support community capacity for people with IDD and specific support needs, including those with behavioral support needs and ASD. The stabilization home program was approved to expand in Illinois' FY24 budget.

Demographic changes, several of which were statistically significant compared to other fiscal years, occurred in FY20. It's difficult to determine why this is, but considering the pandemic began in FY20, its potentially linked to that.

Perpetual funding challenges plague Illinois and the country in the provision of supports for people with IDD. 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 (DSPs). 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 permanently implement some of the Guidehouse rate study recommendations. One recommendation related to the pay for DSPs. The FY24 Illinois budget included a $2.50/hour increase for DSPs providing supports in the community and in ICFs.

Additional research should be completed to better understand the issues around transitions from SODCs. In particular, it is difficult 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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