

An Analysis of Movement from Illinois State-Operated Developmental Centers:

Transitions between July 1, 2016 – December 31, 2018

Report prepared by:

Caitlin Crabb, PhD, MPH

Kelly Hsieh, PhD &

Tamar Heller, PhD

Institute on Disability and Human Development

University of Illinois at Chicago

June 2020

**DISABILITY AND
HUMAN
DEVELOPMENT
COLLEGE OF
APPLIED HEALTH
SCIENCES**



*This project was funded by the Illinois Department of Human Services, Division of
Developmental Disabilities*

Acknowledgements

Many thanks to the Illinois Department of Human Services, Division of Developmental Disabilities (DHS-DDD) and staff at each of the State-Operated Developmental Centers for assisting in gathering this information for submission. Special thanks to Lana Waselewski and Rosemary Hoch for coordinating the data collection and serving as the main contacts for the evaluation team. We especially appreciate their quick responses to questions that we had about the data and how it is used and tracked.

Authors

Caitlin Crabb, PhD, MPH, Research Specialist
Institute on Disability and Human Development (IDHD), University of Illinois at Chicago

Kelly Hsieh, PhD, Research Associate Professor and Interim Associate Director
Institute on Disability and Human Development (IDHD), University of Illinois at Chicago

Suggested Citation

Crabb, C. & Hsieh, K. (2020). *An Analysis of Movement from Illinois State-Operated Developmental Centers: Transitions between July 1, 2016 – December 31, 2018*. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

Table of Contents

Acknowledgements	ii
Authors.....	ii
Suggested Citation	ii
Table of Contents	iii
Table of Tables and Figures	iv
Executive Summary.....	vi
Findings.....	vi
Themes	viii
Introduction	1
Methods	3
Results	4
Question 1. How many transitions occurred out of Illinois SODCs from July 1, 2016 through December 31, 2018?	4
Question 2. What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from July 1, 2016 through December 31, 2018?.....	5
Question 3. To what type of residential setting did individuals transition from July 1, 2016 through December 31, 2018?	10
Question 4. To what extent did individuals remain in their post-transition setting from July 1, 2016 through December 31, 2018?	11
Question 5. Why did people return to a SODC and did they receive TA from July 1, 2016 through December 31, 2018?	12
Question 6. How do demographics and characteristics of persons who transitioned compare across residential settings from July 1, 2016 through December 31, 2018?.....	15
Question 7. What are the demographics and characteristics of people who died from July 1, 2016 through December 31, 2018?	16
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 between July 1, 2016 and December 31, 2018?.....	18
Conclusion	19
Answers to Evaluation/Research Questions	19
Themes	19
References.....	24

Table of Tables and Figures

Table 1: SODC Transitions by Fiscal Year4

Table 2: Demographics by Fiscal Year (July 1, 2016 – December 31, 2018)6

Figure 1: Percentage of Psychiatric Diagnosis of Individuals Transitioning by Fiscal Year (July 1, 2016 – December 31, 2018).....6

Table 3: Psychiatric Diagnosis by Fiscal Year (July 1, 2016 – December 31, 2018).....7

Figure 2: Level of ID by Fiscal Year (July 1, 2016 – December 31, 2018).....8

Table 4: Frequency of ASD Diagnosis by Fiscal Year (July 1, 2016 – December 31, 2018).....8

Table 5: ICAP Service Level Scores9

Table 6: ICAP Service Level Scores by Fiscal Year (July 1, 2016 – December 31, 2018).....9

Table 7: HRST Health Risk Levels9

Table 8: HRST Health Risk Levels (July 1, 2016 – December 31, 2018).....10

Table 9: Discharge Setting by SODC Discharged From (July 1, 2016 – December 31, 2018)...10

Table 10: Discharge Settings by Fiscal Year (July 1, 2016 – December 31, 2018).....11

Table 11: Current Status of Transitioned Individuals by Fiscal Year (July 1, 2016 – December 31, 2018).....11

Figure 3: Current Status of Transitions from a SODC to a CILA: July 1, 2016 – December 31, 2018 (n = 64).....12

Table 12: Characteristics of Transitions to and Remained in the Community by Fiscal Year (July 1, 2016 – December 31, 2018).....12

Figure 4: Frequency of Return to a SODC from a Non-SODC Post-Transition Placement: July 1, 2016 – December 31, 2018 (n = 190).....13

Figure 5: Reasons for Return to a SODC from a Non-SODC Post-Transition Setting: July 1, 2016 – December 31, 2018 (n = 37).....13

Table 13: Receipt of Technical Assistance for SODC Returners by Center.....14

Figure 6: Reason for Return to SODC from a Non-SODC Post-Transition Setting by TA Received: (July 1, 2016 – December 31, 2018).....15

Table 14: Reason for Return to a SODC by Non-SODC Post-Transition Placement: (July 1, 2016 – December 31, 2018).....15

Table 15: Comparing Characteristics of Transitions by Post-Transition Residential Setting (July 1, 2016 – December 31, 2018).....16

Table 16: Characteristics of Individuals who Died at SODC: July 1, 2016 – December 31, 2018 (n = 41).....17

Table 17: Comparing Characteristics of Individuals who Died across Settings: July 1, 2016 – December 31, 2018 (n = 63).....17

Table 18: Characteristics of Individuals who Transitioned to Short-Term Nursing Facilities: July 1, 2016 – December 31, 2018 (n = 25).....18

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 at Chicago to conduct an analysis of transitions out of state-operated developmental centers (SODCs) from July 1, 2016 to December 31, 2018. 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, Rizzolo, & Heller, 2010), from July 1, 2008 through June 30, 2009 (Lulinski-Norris, Rizzolo, & Heller, 2012), from July 1, 2009 through June 30, 2012 (Vasudevan, Rizzolo, Heller, & Lulinski, 2015), and from January 1, 2013 through June 30, 2016 (Owen, Crabb, & Langi, 2017) 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 May 2020.

Findings

How many individuals transitioned out of Illinois SODCs from July 1, 2016 through December 31, 2018?

- There were 207 live transitions out of SODCs in this timeframe. The number of transitions across the three years was relatively equal when doubling the number of transitions in FY2019, as the data only included the first half of FY2019.
- The 207 live transitions represent 200 people, seven of whom transitioned twice.
- There were also 41 transitions because the persons died within the SODC.

What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from July 1, 2016 through December 31, 2018?

- The average age of people who transitioned out of SODCs (live transitions) was 46.8 years of age, and the majority of the live transitions out of SODCs (76.5%) were male. Over half of people who transitioned had family members as their guardian (52.0%), while 24% had a State guardian. On average, people who transitioned had lived in the SODC for 12.7 years, ranging from less than a year to 51 years. Most people who transitioned were White (65.0%) though the majority that transitioned in FY2019 were non-White (54.8%). The data for people remaining in SODCs is not available for us to assess, so we cannot determine if demographic characteristics of those who transitioned out of SODCs are different from those who remain in SODCs. It is not possible for the evaluation team to assess whether these demographic characteristics differed from the population of people remaining in SODCs.
- Over half (58.0%) of people who transitioned had at least one psychiatric diagnosis, ranging from 49.3% in FY2017 to 67.5% in FY2018. The most frequent psychiatric diagnoses were mood disorders (27.5%) and psychotic disorders (21.0%). In addition to psychiatric diagnoses, 7.0% of people who transitioned were diagnosed with autism

spectrum disorder (ASD) and 4.5% were diagnosed with Pervasive Developmental Disorder.

- People who transitioned had varying levels of intellectual disability. Over one third had a profound intellectual disability (33.5%). People who transitioned had an average Inventory for Client and Agency Planning (ICAP) Service Level score of 53.6, 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 2.8 (between low and moderate risk) and over one third (35.0%) scored in the high-risk levels (≥ 4 HRST score). Together, these indicate that people who transitioned had a variety of disability diagnoses and personal care and health needs.

To what type of residential setting did individuals transition from July 1, 2016 through December 31, 2018?

- Of the 207 live transitions, less than a third (31.4%) went to CILAs, 26.6% went to Skilled Nursing Facilities, 9.2% went to jail, 8.2% went to another SODC, 7.7% went to an ICF/DD, 6.3% went to a family home, 6.3% went to an “other” setting, and 4.3% went to a mental health center.

To what extent did individuals remain in their post-transition setting from July 1, 2016 through December 31, 2018?

- For those whose data was available, 47.8% of transitions had a continuous placement, meaning that they were still in the setting that they transitioned to. 21.7% returned to a SODC and 16.4% died.
- Of the 64 transitions that went to a CILA and who had a current status, nearly three-quarters remained in the same setting and with the same service provider, while 1% remained with the same provider but in a different residence in the community and 5% remained in the community but with another provider. Only 2% of people who transitioned to a CILA died and 20% returned to a SODC.
- Of people who originally transitioned to a CILA, and remained in a CILA, either with the same provider or another and either in the original residence or another one, they were middle-aged (43.7 years on average), had a HRST score of 1.8 (lowest to low risk), had an IQ of 46.5, and had an ICAP Service Level score of 59.9 (Level 3 – regular personal care and/or close supervision).

Why did people return to a SODC and did they receive TA from July 1, 2016 through December 31, 2018?

- Of the 190 transitions from a SODC to a non-SODC setting, 37 returned to a SODC (19.5%). Most (41.0%) returned for behavioral reasons, followed by short-term therapy (27%), other (24%), and medical (5%); 3% were missing a reason for return.
- Technical Assistance (TA) was provided to the majority of people who returned for a behavioral reason (12 of the 15 received TA: 11 received only behavioral TA and one received both behavioral and medical TA). TA was not provided for any of those that

returned for a medical reason or another reason. Only one received TA (behavioral) upon their return from short-term therapy.

- Of the 13 people who returned to a SODC from a CILA, all did so because of a behavioral reason.

How do the demographics and characteristics of persons who transitioned compare across residential settings from July 1, 2016 through December 31, 2018?

- Those transitioning to community settings (CILA and family settings), were generally younger (CILA: 41.1 mean age, family: 32.0 mean age).
- People in community settings (CILA and family settings) had lower health risks, especially compared to those in institutional settings like ICF/DDs, SNFs, and SODCs. People transitioning to SNFs had the highest health risks (HRST score of 4.5 out of 6).
- People who had been in SODCs the longest generally transferred to institutional settings including ICF/DDs (average LOS = 24.6 years) and SNFs (average LOS = 24.7 years).

What are the demographics and characteristics of people who died since transitioning from a SODC from July 1, 2016 through December 31, 2018?

- A total of 63 people died at a SODC (41) or after they transitioned out of a SODC (22 people).
- Individuals who died in an "Other" setting had the highest health risk and the lowest IQ.
- People who died at a SODC had a mean age of 64.1 years, a HRST of 4.5 (high moderate to high health risk), and had been in the SODC for an average of 23.3 years. They also had an ICAP Service Level score of 31.8 (Level 2 – Extensive personal care and/or constant supervision). All had an ID, 31.7% had a psychiatric disorder, and 7.3% had an ASD diagnosis.

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 between July 1, 2016 and December 31, 2018?

- 25 people (representing 28 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 58.2 years of age with an average length of stay in a SODC of 19.1 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 25.1 which indicates the highest level of support needs and a mean IQ of 18.2.
- These individuals had significant health and support needs.

Themes

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

- ❖ Changing demographics and characteristics of the people transitioning:
 - The percentage of live transitions to CILAs increased each year, beginning with 28.2% in FY2017 and ending with 40.5% in FY2019.

- On average, most of those who transitioned were white, yet in FY2019, the majority of those who transitioned were non-White (54.8%).
 - The average age of those who transitioned decreased across the three years, starting with 49.5 years in FY2017 and ends with 42.9 years in FY2019.
 - Those with family guardians decreased each year, beginning with 60% in FY2017 and ending with 42.9% in FY2019
 - ICAP service level score increased each year, beginning with 51.5 and ending with 56.2 in FY2019, though this didn't change service levels categories.
 - Mean HRST decreased over the three years, beginning with 3.0 in FY2017 and ending with 2.5 in FY2019. The percentage of people in the high risk HRST group (HRST \geq 4) also decreased over the years.
 - The mean age of those who transitioned to CILAs and remained in them after their transition decreased over the three years (FY2017: 49, FY2019: 40.2); mean IQ decreased, HRST remained stable.
- ❖ Challenges in community settings for people with ID and a psychiatric diagnosis.
- The majority of those who transitioned out of SODCs had a psychiatric diagnosis (58%). The rate of transition for people with psychiatric diagnoses increased from FY2017 to FY2018 (from 49.3% to 67.5%) but then decreased again in FY2019 (54.8%).
 - All of those that returned to a SODC from a CILA did so for behavioral reasons between FY2017 and FY2019.
 - While most of the 15 people who returned to an SODC for a behavioral reason received technical assistance, three people (20%) returned before they were able to receive technical assistance.

Introduction

People with intellectual and developmental disabilities (IDD) have historically resided in large congregate settings like state-operated developmental centers and nursing facilities that prioritized medical care. In 1967, the institutional census of people with IDD peaked and began its subsequent decline (Scott, Lakin, & Larson, 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 and community living is generally touted as the paragon of habilitation for people with IDD across the spectrum. The *State of the States in Developmental Disabilities* project tracks state spending on people with IDD in community settings and in SODCs. They estimate that 173 public institutions in 42 states and the District of Columbia will have ceased operations by 2020 (Braddock et al., 2015). As of June 30, 2016, 139 institutions were open across the United States compared to 374 between 1960 and 2015 (Larson et al., 2018).

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 between FY2017 and FY2019, a timeframe when Illinois had seven active SODCs. In FY2015, only New York, Texas, and Ohio had more institutions than Illinois and Illinois ranked 47th among the states in the percentage of funding it provides for community IDD services (Braddock, Hemp, Tanis, Wu, & Haffer, 2017).

Research has tied transitions out of institutions and into the community to positive outcomes (Chowdhury & Benson, 2011; Heller, Schindler, & Rizzolo, 2008; Kozma, Mansell, & Beadle-Brown, 2009; Lakin, Larson, & Kim, 2011; Rizzolo, Larson, & Hewitt, 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-Norris, 2014).

The Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago has maintained a database of transitions out of SODCs in Illinois since 2001. The last report in this series was completed in 2017 (Owen et al., 2017), and in the spring of 2020, the Illinois Department of Human Services, Division of Developmental Disabilities (DHS-DDD) extended the database to include transitions from July 1, 2016 through December 31, 2018. The current report is very similar to the 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. All data in this report are from July 1,

2016 to December 31, 2018. Furthermore, July 1, 2018 – December 31, 2018 is referred to as FY2019 in this report, even though it is only half of the fiscal year.

The questions that this report answers are:

- 1) How many individuals transitioned out of Illinois SODCs from July 1, 2016 through December 31, 2018?
- 2) What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from July 1, 2016 through December 31, 2018?
- 3) To what type of residential setting did individuals transition from July 1, 2016 through December 31, 2018?
- 4) To what extent did individuals remain in their post-transition setting from July 1, 2016 through December 31, 2018?
- 5) Why did people return to a SODC and did they receive TA from July 1, 2016 through December 31, 2018?
- 6) How do the demographics and characteristics of persons who transitioned compare across residential settings from July 1, 2016 through December 31, 2018?
- 7) What are the demographics and characteristics of people who died since transitioning from a SODC from July 1, 2016 through December 31, 2018?
- 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 between July 1, 2016 and December 31, 2018?

Methods

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

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 May 2020:

- 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) 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
- 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 post-transition

Data was coded and then analyzed using SPSS 24.0. 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.

Question 1. How many transitions occurred out of Illinois SODCs from July 1, 2016 through December 31, 2018?

Between July 1, 2016 and December 31, 2018 there were a total of 207 live transitions out of the Illinois State-Operated Developmental Center (SODC) system. These transitions represented 200 people, some of whom transitioned more than once into various settings. Of the 200 individuals who had live transitions during the time period, 193 transitioned once (96.5%) and seven transitioned twice (3.5%). Questions one through six focus on these 207 live transitions, while question seven focuses on transitions from SODCs where the person died in the SODC during this period (41 people) and on people who died in their transition setting following discharge (22 people) from a SODC. Question eight focuses on 25 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.

As shown in Table 1, in terms of the number of live transitions, FY2018 saw the most transitions from SODCs (87), followed by FY2017 (78). The data only includes half of FY2019, so doubling the state transitions during that half of the fiscal year would equal 84 transitions across that entire fiscal year, which closely matches the previous two fiscal years. The Choate Developmental Center (Choate) accounted for the most transitions over this period (85, 41.1%). The second highest number of transitions were from Governor Samuel H. Shapiro Developmental Center (Shapiro) with 64 (30.9%) transitions out of Shapiro. Together, Choate and Shapiro accounted for nearly three-quarters of the transitions from SODCs in Illinois. Ludeman Developmental Center (Ludeman) transitioned 12.1% of the total transitions from July 1, 2016 through December 31, 2018. The remaining SODCs, including Kiley Developmental Center (Kiley), Murray Developmental Center (Murray), Fox Developmental Center (Fox), and Jack Mabley Developmental Center (Mabley) each transitioned between 1.4% and 7.2% of the total transitions from July 1, 2016 through December 31, 2018.

Table 1: SODC Transitions by Fiscal Year

SODC	FY2017	FY2018	FY2019*	FY2017-FY2019	% of Total by SODC
Choate	33	30	22	85	41.1%
Fox	3	0	0	3	1.4%
Jack Mabley	0	2	1	3	1.4%
Kiley DC	6	8	1	15	7.2%
Ludeman	8	14	3	25	12.1%
Murray	6	3	3	12	5.8%
Shapiro	22	30	12	64	30.9%
Total	78	87	42	207	
% of Total for FY	37.7%	42.0%	20.3%		

*FY19 only includes half of the fiscal year from July 1, 2018 through December 31, 2018

Question 2. What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from July 1, 2016 through December 31, 2018?

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 from July 1, 2016 through December 31, 2018. If an individual transitioned more than once 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

Of the 200 individuals who transitioned out of the seven Illinois SODCs during the FY2017-2019 study period, the youngest was 19 years and the oldest was 94. The average age was 46.8 (SD = 18.0) years at the time of transition from July 1, 2016 through December 31, 2018. FY2017 had the highest average age of 49.5 years (SD = 17.0), while FY2019 was the lowest at 42.9 years of age (SD = 15.9).

Length of Stay (LOS)

People who transitioned out of a SODC from July 1, 2016 through December 31, 2018 had lived in the SODC for an average of 12.7 years, ranging from less than a year to 51 years (SD = 15.3).

Gender

Across the years, most of the individuals who transitioned out of the SODCs were male (76.5%), and the percentage was consistently around 75% during all three fiscal years.

Race

Across FY2017-FY2019, most people who transitioned out of SODCs were white (65.0%). However, the majority of those who transitioned in FY2019 were non-white (54.8%).

Guardianship Status

Approximately half of the individuals who transitioned out of SODCs from July 1, 2016 through December 31, 2018 had family members as their guardians (52.0%). The percentage of people with a family member as a guardian ranged from 42.9% in FY2019 to 60.0% in FY2017. About a quarter of the 200 individuals that transitioned had a State guardian (48, 24.0%) or were legally competent (45, 22.5%).

Table 2: Demographics by Fiscal Year: July 1, 2016 – December 31, 2018

	FY2017 (n = 75)		FY2018 (n = 83)		FY2019 (n = 42)		FY2017-FY2019 (n = 200)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Age (years)	49.5	17.0	46.4	19.6	42.9	15.9	46.8	18.0
Length of Stay (years)	13.1	14.8	13.0	16.2	11.3	14.6	12.7	15.3
	n	%	n	%	n	%	n	%
Gender								
Male	60	80.0	61	73.5	32	76.2	153	76.5
Female	15	20.0	22	26.5	10	23.8	47	23.5
Race								
White	49	65.3	62	74.7	19	45.2	130	65.0
Non-White	26	34.7	21	25.3	23	54.8	70	35.0
Guardian Status								
Legally competent	16	21.3	18	21.7	11	26.2	45	22.5
State guardian	14	18.7	23	27.7	11	26.2	48	24.0
Family Guardian	45	60.0	41	49.4	18	42.9	104	52.0
Non-Family Guardian	0	0.0	1	1.2	1	2.4	2	1.0
Other/unknown	0	0.0	0	0.0	1	2.4	1	0.5

Psychiatric Diagnosis

Of the 200 individuals who transitioned during FY2017 through FY2019, 116 people (58.0%) had at least one psychiatric diagnosis. Figure 1 illustrates the percentages of those transitioning from July 1, 2016 through December 31, 2018 with a diagnosed psychiatric disorder.

Figure 1: Percentage of Psychiatric Diagnosis of Individuals Transitioning by Fiscal Year July 1, 2016 – December 31, 2018

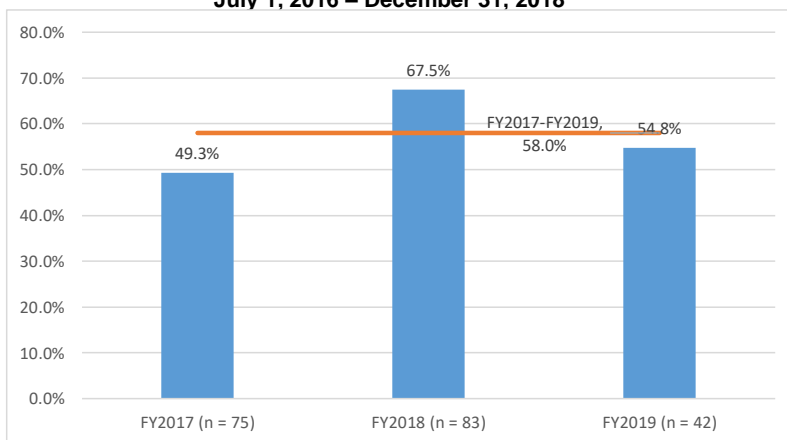


Table 3 describes the percentage of individuals diagnosed with a psychiatric disorder by fiscal year. Between July 1, 2016 and December 31, 2018, the majority had a psychiatric diagnosis (58.0%); over a third had one psychiatric diagnosis (34.0%) and 24.0% had two or more psychiatric diagnoses. Between July 1, 2016 through December 31, 2018 (n = 200), the most common psychiatric diagnoses were mood disorder (27.5%), psychotic disorder (21.0%), impulse control disorder (10.0%), childhood disorders (10.0%), personality disorders (7.5%), and anxiety disorders (6.5%).

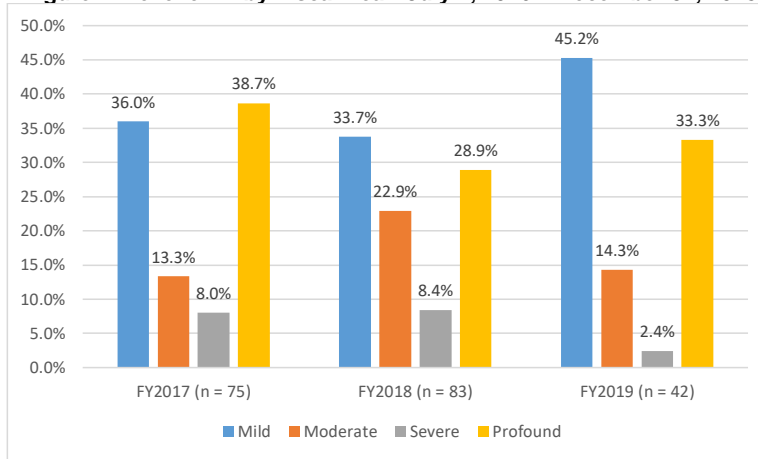
Table 3: Psychiatric Diagnosis by Fiscal Year: July 1, 2016 – December 31, 2018

	FY2017 (n = 75)		FY2018 (n = 83)		FY2019 (n = 42)		FY2017- FY2019 (n = 200)	
	n	%	n	%	n	%	n	%
Number of psychiatric diagnoses								
0	38	50.7%	27	32.5%	19	45.2%	84	42.0%
1	19	25.3%	37	44.6%	12	28.6%	68	34.0%
2	13	17.3%	14	16.9%	7	16.7%	34	17.0%
3	5	6.7%	3	3.6%	3	7.1%	11	5.5%
4	0	0.0%	2	2.4%	1	2.4%	3	1.5%
Psychiatric diagnosis*								
Mood	16	21.30%	32	38.60%	7	16.70%	55	27.50%
Psychotic	15	20.00%	19	22.90%	8	19.00%	42	21.00%
Impulse	10	13.30%	5	6.00%	5	11.90%	20	10.00%
Childhood	6	8.00%	8	9.60%	6	14.30%	20	10.00%
Personality	3	4.00%	7	8.40%	5	11.90%	15	7.50%
Anxiety	4	5.30%	6	7.20%	3	7.10%	13	6.50%
Substance	1	1.30%	2	2.40%	1	2.40%	4	2.00%
Sexual	0	0.00%	0	0.00%	1	2.40%	1	0.50%
Adjustment	1	1.30%	0	0.00%	0	0.00%	1	0.50%
*Not mutually exclusive								

Level of Intellectual Disability

Of the 200 individuals who transitioned out of a SODC between July 1, 2016 and December 31, 2018, nearly all (98%) had a diagnosis of intellectual disability (ID). Figure 2 illustrates the level of ID by fiscal year. Over a third of those who transitioned during the time period had a mild intellectual disability (37.0%) or a profound intellectual disability (33.5%).

Figure 2: Level of ID by Fiscal Year: July 1, 2016 – December 31, 2018



Autism Spectrum Disorder (ASD) Diagnosis

During the three years, 7.0% of people who transitioned had a diagnosis of autism spectrum disorder (ASD) while 4.5% had pervasive developmental disorder (PDD). Table 4 shows the frequency of these diagnoses by fiscal year.

Table 4: Frequency of ASD Diagnosis by Fiscal Year: July 1, 2016 – December 31, 2018

	FY2017 (n = 75)		FY2018 (n = 83)		FY2019 (n = 42)		FY2017- FY2019 (n = 200)	
	n	%	n	%	n	%	n	%
No ASD Diagnosis	69	92.0	70	84.3	38	90.5	177	88.5
Autism	3	4.0	9	10.8	2	4.8	14	7.0
PDD	3	4.0	4	4.8	2	4.8	9	4.5

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 Table 5.

Table 5: ICAP Service Level Scores

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 between from July 1, 2016 and December 31, 2018 was 9 - 95. The average ICAP Service Level Score for individuals who transitioned between July 1, 2016 and December 31, 2018 was 53.6 (SD = 23.2), which indicates an average need for regular personal care and close supervision. Table 6 describes percentage of individuals in each ICAP Service Level Score category by fiscal year. Overall, most individuals who transitioned were in the Level 4 category across FY2017-FY2019 (28.9%). Level 4 indicates limited personal care and/or regular supervision.

Table 6: ICAP Service Level Scores by Fiscal Year: July 1, 2016 – December 31, 2018

	FY2017 (n = 75)	FY2018 (n = 81)	FY2019 (n = 41)	FY2017- FY2019 (n = 197)
Level 1	30.7%	16.0%	19.5%	22.3%
Level 2	18.7%	24.7%	19.5%	21.3%
Level 3	18.7%	29.6%	24.4%	24.4%
Level 4	29.3%	25.9%	34.1%	28.9%
Level 5	2.7%	3.7%	2.4%	3.0%

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, as indicated in Table 7.

Table 7: HRST Health Risk Levels

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

HRST scores for individuals who transitioned from July 1, 2016 through December 31, 2018 range from level 1 to level 6 and the average HRST score was 2.8 (SD = 1.7), which is in the

moderate risk level. Table 8 shows the percentage of people with high HRST scores (≥ 4) and the mean HRST score for each fiscal year. FY2017 had the highest percentage of people in the high HRST score group with a mean HRST of 3.0 (moderate risk level). FY2019 had the lowest percentage of people in the high HRST score group with a mean HRST of 2.5 (low to moderate risk level).

Table 8: HRST Health Risk Level: July 1, 2016 – December 31, 2018

	FY2017 (n = 67)	FY2018 (n = 72)	FY2019 (n = 38)	FY2017-FY2019 (n = 177)
% High HRST (≥ 4)	37.3%	34.7%	31.6%	35.0%
Mean HRST	3.0	2.9	2.5	2.8

Question 3. To what type of residential setting did individuals transition from July 1, 2016 through December 31, 2018?

Table 9 describes the percentage of transitions from each SODC to various types of residential settings between July 1, 2016 and December 31, 2018. Though post-transition settings varied by SODC, transitions out of a SODC and into a CILA setting made up over a quarter (31.4%) of the 207 transitions during that period. The second most common post-transition setting was a Skilled Nursing Facility (SNF), which made up 26.6% of the transitions during that period. Approximately 9.2% of transitions were to jail, followed by 8.2% of transitions to another SODC. 7.7% transitioned to an Intermediate Care Facility for Developmental Disabilities (ICF/DD). A small number of transitions went to a State-Operated Mental Health Center (MHC; 4.3%). 6.3% of individuals moved in with a family member. The remaining 6.3% transitioned to other settings.

Mabley had the highest percent of transitions that went to CILAs (66.7%) while Fox had no transitions to CILAs: all of the transitions from Fox went to ICF/DDs.

Table 9: Discharge Setting by SODC Discharged from July 1, 2016 – December 31, 2018

	Choate (n = 85)	Fox (n = 3)	Mabley (n = 3)	Kiley (n = 15)	Ludeman (n = 25)	Murray (n = 12)	Shapiro (n = 64)	Total (n = 207)
CILA	38.8%	0.0%	66.7%	53.3%	16.0%	33.3%	21.9%	31.4%
Jail	22.4%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	9.2%
Family	11.8%	0.0%	0.0%	6.7%	4.0%	0.0%	1.6%	6.3%
ICF/DD	4.7%	100.0%	33.3%	0.0%	16.0%	8.3%	4.7%	7.7%
Other SODC	8.2%	0.0%	0.0%	0.0%	4.0%	25.0%	9.4%	8.2%
MHC	4.7%	0.0%	0.0%	0.0%	20.0%	0.0%	0.0%	4.3%
SNF	0.0%	0.0%	0.0%	20.0%	36.0%	33.3%	60.9%	26.6%
Other	9.4%	0.0%	0.0%	20.0%	4.0%	0.0%	1.6%	6.3%

Table 10 illustrates the transition settings by fiscal year. The lowest percentage of transitions to a CILA happened in FY2017 (28.2%) while the highest percentage of transitions to CILAs (40.5%) happened in FY2019.

Table 10: Discharge Settings by Fiscal Year: July 1, 2016 – December 31, 2018

	FY2017 (n = 78)	FY2018 (n = 87)	FY2019 (n = 42)	FY2017-FY2019 (n = 207)
CILA	28.2%	29.9%	40.5%	31.4%
Jail	10.3%	9.2%	7.1%	9.2%
Family	7.7%	4.6%	7.1%	6.3%
ICF/DD	10.3%	6.9%	4.8%	7.7%
Other SODC	9.0%	4.6%	14.3%	8.2%
MHC	1.3%	8.0%	2.4%	4.3%
SNF	24.4%	32.2%	19.0%	26.6%
Other	9.0%	4.6%	4.8%	6.3%

Question 4. To what extent did individuals remain in their post-transition setting from July 1, 2016 through December 31, 2018?

Regulations only require the Department of Human Services follow individuals for one year after they transitioned. Because data for this report covers FY2017 through the first half of FY2019, 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 (May 2020). Therefore, the current status actually represents the 12-month follow-up. Unfortunately, the current status of 11.6% of the transitions during this period are unknown. Of those for whom data was available, 47.8% had maintained a continuous placement in their new setting following that transition.

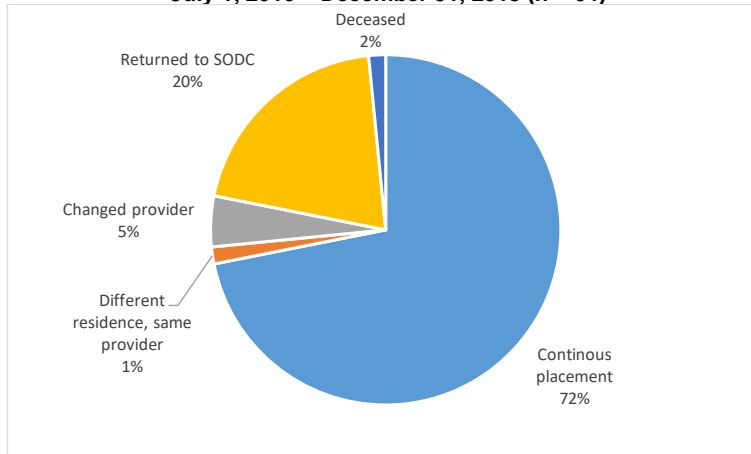
Table 11: Current Status of Transitioned Individuals by Fiscal Year: July 1, 2016 – December 31, 2018

	FY2017 (n = 78)	FY2018 (n = 87)	FY2019 (n = 4)	FY2017- 2019 (n = 207)
Continuous placement	50.0%	41.4%	57.1%	47.8%
Different residence, same provider	1.3%	0.0%	0.0%	0.5%
Changed provider	1.3%	1.1%	2.4%	1.4%
Returned to SODC	10.3%	33.3%	19.0%	21.7%
Deceased	24.4%	11.5%	11.9%	16.4%
Unknown	11.5%	12.6%	9.5%	11.6%
Missing	1.3%	0.0%	0.0%	0.5%

Of the 64 transitions from a SODC to a CILA from July 1, 2016 through December 31, 2018 (Figure 3) with a current status, nearly three-quarters (72%) remained at the same home and

with the same service provider (as of December 31, 2018). A fifth of those discharged to CILAs returned to a SODC. One moved residences but stayed with the same provider (1.6%) while 5% moved homes and switched providers. One transition discharged to a CILA died (1.6%).

**Figure 3: Current Status of Transitions from a SODC to a CILA:
July 1, 2016 – December 31, 2018 (n = 64)**



Individuals who transitioned to a CILA and remained in the community (either with the same community provider or new community provider) had a mean age of 43.7 years, mean HRST score of 1.8, mean ICAP Service Level score of 59.9, and mean IQ of 46.5 (Table 12).

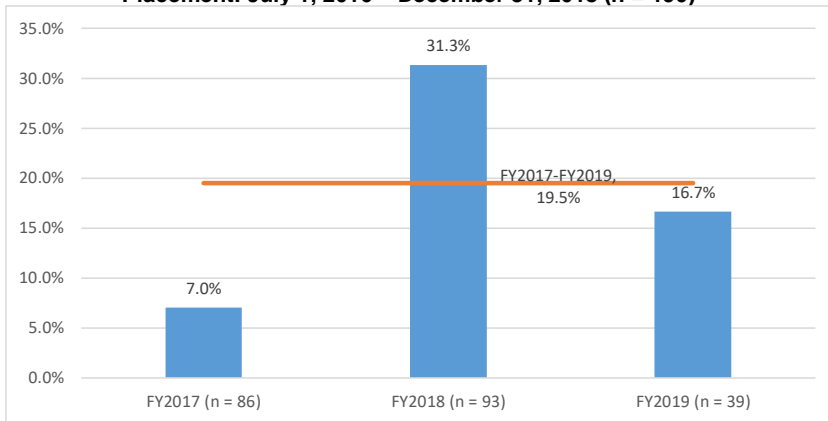
**Table 12: Characteristics of Transitions to and Remained in the Community
by Fiscal Year: July 1, 2016 – December 31, 2018**

	FY2017 (n = 18)	FY2018 (n = 18)	FY2019 (n = 14)	FY2017-2019 (n = 50)
Age (years)	49.0	41.0	40.2	43.7
HRST	1.8	1.8	1.9	1.8
IQ	52.7	43.5	42.7	46.5
ICAP Service Level Score	64.6	53.0	62.9	59.9

Question 5. Why did people return to a SODC and did they receive TA from July 1, 2016 through December 31, 2018?

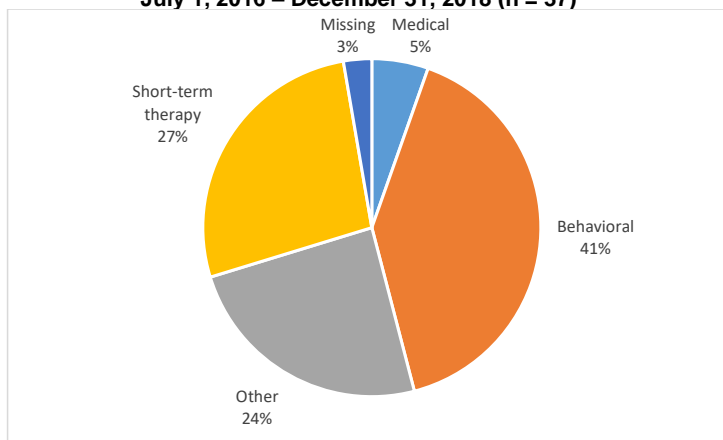
Between July 1, 2016 and December 31, 2018, of the 190 transitions from a SODC to a non-SODC setting, 37 returned to a SODC (19.5%). In FY2017, 7.0% returned to a SODC, 31.3% in FY2018, and 16.7% in FY2019 (Figure 4).

Figure 4: Frequency of Return to a SODC from a Non-SODC Post-Transition Placement: July 1, 2016 – December 31, 2018 (n = 190)



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. Figure 5 illustrates the reasons individuals returned to a SODC after discharge. Of the 37 returns to a SODC, the main reason for return was behavioral (41%), followed by short-term therapy (27%), other (24%) and medical (5%). One was missing a reason for return (3%), see Figure 5.

Figure 5: Reasons for Return to a SODC from a Non-SODC Post-Transition Setting: July 1, 2016 – December 31, 2018 (n = 37)



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 (DLA) and is outlined in Illinois Administrative Code, Title 59, Chapter 1, Part 25 entitled “Recipient Discharge/Linkage/Aftercare.” Technical Assistance is support provided in addition to DLA, and is offered for

individuals experiencing behavioral and/or medical concerns for which the service provider requires input from a specific discipline. Technical Assistance 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 technical assistance. Choate and Shapiro had the highest number of returns (each 12) with 58.3% of those receiving TA at Choate and 25.0% receiving TA at Shapiro. Kiley provided the highest percentage of returners with TA (66.7%, 2 out of 3 returners). Ludeman did not provide TA to any of the eight returners.

Table 13: Receipt of Technical Assistance for SODC Returners by Center

SODC	Number of Returns	Number Receiving TA	Percent Receiving TA
Choate	12	7	58.3%
Fox	0	-	-
Kiley	3	2	66.7%
Ludeman	8	0	0.0%
Mabley	0	-	-
Murray	2	1	50.0%
Shapiro	12	3	25.0%
Total	37	13	35.1%

Figure 6 compares the reason (medical, behavioral, other, and short-term therapy) for an individual's return to a SODC by whether or not they received medical, behavioral, or medical and behavioral TA. Data is presented from July 1, 2016 through December 31, 2018. Neither of the two transitions back to a SODC because of medical reasons received TA. Conversely, for those who returned to a SODC because of behavioral reasons, 11 (73.3%) received behavioral TA, and one (6.7%) received medical and behavioral TA; three did not receive any TA (20.0%). Of the nine transitions that returned for another reason, none received any TA. Lastly, of those returning to a SODC for short-term therapy, 10% received behavioral TA and 90% did not receive any TA.

Figure 6: Reason for Return to SODC from a Non-SODC Post-Transition Setting by TA Received: July 1, 2016 – December 31, 2018

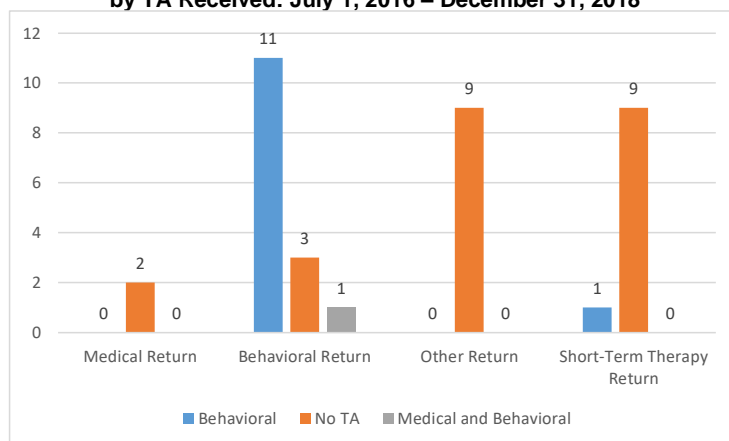


Table 14 compares the reason (medical, behavioral, other, and short-term therapy), for an individual's return to a SODC by the setting from which they returned to the SODC. Those that returned from a CILA did so for behavioral reasons (100%). Of the 15 that returned to a SODC from a SNF, eight did so for short-term therapy (53.3%), five did so for another reason (33.3%), and one returned for a medical reason (6.7%).

Table 14: Reason for Return to a SODC by Non-SODC Post-Transition Placement: July 1, 2016 – December 31, 2018

	24-Hour CILA (n = 13)	Jail (n = 2)	Family (n = 2)	MH Hospital (n = 4)	SNF (n = 15)	Other (n = 1)
Medical	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (6.7%)	1 (100%)
Behavioral	13 (100%)	0 (0%)	2 (100%)	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	2 (100%)	0 (0%)	2 (50%)	5 (33.3%)	0 (0%)
Short-term therapy	0 (0%)	0 (0%)	0 (0%)	2 (50%)	8 (53.3%)	0 (0%)
Missing	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (6.7%)	0 (0%)

Question 6. How do demographics and characteristics of persons who transitioned compare across residential settings from July 1, 2016 through December 31, 2018?

In the instance that an individual transitioned more than once, 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 mental health center (mean age = 29.0) and those who went to jail (mean age = 29.4). Those who transitioned to community settings, including CILAs and family settings, were generally younger (41.1 mean

age for CILAs and 32.0 mean age for family settings) than other transition settings, such as SNFs, ICF/DDs, and other settings. Those in community settings also had lower health risks than other settings, specifically lower than institutional settings including ICF/DDs, SNFs, and SODCs. In fact, those that transitioned to SNFs had the highest health risks and the lowest IQs. People who had been in the SODCs the longest generally transferred to other institutional settings including ICF/DDs and SNFs. People who went to jail had the highest ICAP service level scores indicating the lowest level of support need.

Table 15: Comparing Characteristics of Transitions by Post-Transition Residential Setting: July 1, 2016 – December 31, 2018

	CILA (n = 65)	Jail (n = 19)	Family (n = 13)	ICF/DD (n = 16)	MHC (n = 9)	SODC (n = 17)	SNF (n = 55)	Other (n = 13)
	mean	mean	mean	mean	mean	mean	mean	mean
Age (years)	41.1	29.4	32.0	59.8	29.0	41.1	64.2	46.0
LOS @ previous SODC (years)	7.3	0.6	2.0	24.6	2.7	6.4	24.7	16.6
HRST	1.9	1.0	1.6	3.3	1.8	3.5	4.5	2.8
ICAP Service Level Score	62.0	78.7	69.5	33.2	64.7	53.8	36.6	46.0
IQ	48.7	63.4	53.6	18.6	58.9	45.5	18.1	33.2
	%	%	%	%	%	%	%	%
Percentage of ID	98.5%	94.7%	92.3%	100.0%	100.0%	100.0%	100.0%	92.3%
Percentage of Psychiatric	70.8%	36.8%	69.2%	31.3%	100.0%	84.6%	47.2%	46.2%
Percentage of ASD	16.9%	5.3%	7.7%	25.0%	0.0%	23.1%	3.8%	7.7%

Question 7. What are the demographics and characteristics of people who died from July 1, 2016 through December 31, 2018?

A total of 63 people died either at a SODC or after they had transitioned out of a SODC from July 1, 2016 through December 31, 2018. 41 people died in a SODC and 22 died elsewhere.

Between July 1, 2016 and December 31, 2018, 13.8% of the total transitions (41 out of 298) died while at a SODC. Table 16 describes the characteristics of the 41 individuals who died while at a SODC between July 1, 2016 and December 31, 2018. On average, the mean age for individuals who died in a SODC was 64.1 years and they had an average length of stay in the SODC of 23.3 years. These individuals had a mean HRST score of 4.5 out of 6 (meaning they had a high-moderate to high health risk). Individuals who died in a SODC generally had “Extensive” ICAP Service Level scores (mean score of 31.8) and a mean IQ of 16.3. This means that the people who died in a SODC needed extensive personal care and had poor

health overall. All 41 individuals had an ID, while 31.7% had at least one psychiatric diagnosis, and 7.3% were also diagnosed with autism spectrum disorder (ASD).

**Table 16: Characteristics of Individuals who Died at SODC:
July 1, 2016 – December 31, 2018 (n = 41)**

	Mean	SD
Age (years)	64.1	13.1
Length of Stay (years)	23.3	15.5
HRST	4.5	1.5
ICAP Service Level Score	31.8	17.1
IQ	16.3	16.1
	N	%
Frequency of ID	41	100.0%
Frequency of Psychiatric Disorder	13	31.7%
Frequency of ASD	3	7.3%

A total of 22 individuals died after transitioning out of a SODC in Illinois between July 1, 2016 and December 31, 2018. About two-thirds of the deaths post-transition did not have a discharge to setting within the data (59.1%) while the others occurred at other settings (40.9%).

Table 17 compares demographic characteristics of individuals who died (n = 63) across settings. The majority of the 63 deaths occurred at a SODC (65.1%), followed by those missing a discharge setting in the data (20.6%), and other settings (14.3%). Individuals that died in a SODC were the oldest (mean age = 64.1 years) and had the lowest average ICAP service level score (31.8, indicating a higher level of support needed). Those who died at other settings had the highest health risk (mean HRST score = 5.1), the highest ICAP service level score (mean score = 37.9) which indicates a lower level of support needed, and the lowest IQ. Those who were missing a discharge location and who died in other settings had an average length of stay in the SODC of about 27 years, compared to 23.3 for those who died in SODCs.

**Table 17: Comparing Characteristics of Individuals who Died across Settings:
July 1, 2016 – December 31, 2018 (n = 63)**

	Missing (n = 13) Mean	SODC (n = 41) Mean	Other (n = 9) Mean
Age (years)	58.6	64.1	61.0
LOS @ previous SODC (years)	27.6	23.3	27.8
HRST	3.5	4.5	5.1
ICAP Service Level Score	36.2	31.8	37.9
IQ	23.2	16.3	12.2

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 between July 1, 2016 and December 31, 2018?

A total of 25 people (representing 28 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 December 31, 2018.

As there were three individuals who transitioned out of SODCs and to short-term nursing homes twice during the time period, the data below includes only the most recent discharge. Table 18 describes the characteristics of the 25 individuals who transitioned to a short-term nursing home between July 1, 2016 and December 31, 2018. On average, the mean age for individuals who transitioned to short-term nursing homes was 58.2 years and they had an average length of stay in the SODC of 19.1 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 “Total” ICAP Service Level scores (mean score of 25.1, the highest level of support needs-total personal care/intensive supervision) and a mean IQ of 18.2. These numbers show that these individuals have extensive health and other support needs. All 25 individuals had an ID, while 44% had at least one psychiatric diagnosis, and 16% were also diagnosed with autism spectrum disorder (ASD).

Table 18: Characteristics of Individuals who Transitioned to Short-Term Nursing Facilities: July 1, 2016 – December 31, 2018 (n = 25)

	Mean	SD
Age (years)	58.2	9.1
Length of Stay (years)	19.1	17.6
HRST	4.2	1.7
ICAP Service Level Score	25.1	15.5
IQ	18.2	15.3
	N	%
Frequency of ID	25	100.0%
Frequency of Psychiatric Disorder	11	44.0%
Frequency of ASD	4	16.0%

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, along with a few overarching themes.

Answers to Evaluation/Research Questions

How many individuals transitioned out of Illinois SODCs from July 1, 2016 through December 31, 2018?

- There were 207 live transitions out of SODCs in this timeframe. The number of transitions across the three years was relatively equal when doubling the number of transitions in FY2019, as the data only included the first half of FY2019.
- The 207 live transitions represent 200 people, seven of whom transitioned twice.
- There were also 41 transitions because the person died within the SODC.

What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from July 1, 2016 through December 31, 2018?

- The average age of people who transitioned out of SODCs (live transitions) was 46.8 years of age, and the majority (76.5%) were male. Over half of people who transitioned had family members as their guardian (52.0%), while 24% had a State guardian. On average, people who transitioned had lived in the SODC for 12.7 years, ranging from less than a year to 51 years. Most people who transitioned were White (65.0%) though the majority that transitioned in FY2019 were non-White (54.8%). It is not possible for the evaluation team to assess whether these demographic characteristics differed from the population of people remaining in SODCs.
- Over half (58.0%) of people who transitioned had at least one psychiatric diagnosis, ranging from 49.3% in FY2017 to 67.5% in FY2018. The most frequent psychiatric diagnoses were mood disorders (27.5%) and psychotic disorders (21.0%). In addition to psychiatric diagnoses, 7.0% of people who transitioned were diagnosed with autism spectrum disorder (ASD) and 4.5% were diagnosed with Pervasive Developmental Disorder.
- People who transitioned had varying levels of intellectual disability. Over one third had a mild or a profound intellectual disability. People who transitioned had an average Inventory for Client and Agency Planning (ICAP) Service Level score of 53.6, 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 level of 2.8 (between low and moderate risk) and over one third (35.0%) scored in the high risk levels (≥ 4 HRST score). Together, these indicate that people who transitioned had a variety of disability diagnoses and personal care and health needs.

To what type of residential setting did individuals transition from July 1, 2016 through December 31, 2018?

- Of the 207 live transitions, almost a third (31.4%) went to CILAs, 26.6% went to Skilled Nursing Facilities, 9.2% went to jail, 8.2% went to another SODC, 7.7% went to an ICF/DD, 6.3% went to a family home, 6.3% went to another setting, and 4.3% went to a mental health center.

To what extent did individuals remain in their post-transition setting from July 1, 2016 through December 31, 2018?

- SODC staff follow-up with people who have transitioned for 12 months; because of those who transitioned more than a year ago, 11.6% have a current status of unknown. For those whose data was available, 47.8% of transitions had a continuous placement, meaning that they were still in the setting that they transitioned to. 21.7% returned to a SODC and 16.4% died.
- Of the 64 transitions that went to a CILA and who had a current status, nearly three-quarters remained in the same setting and with the same service provider, while 1% remained with the same provider but in a different residence in the community and 5% remained in the community but with another provider. Only 2% of people who transitioned to a CILA died and 20% returned to a SODC.
- Of people who originally transitioned to a CILA, and remained in a CILA, either with the same provider or another and either in the original residence or another one, they were middle-aged (43.7 years on average), had a HRST score of 1.8 (lowest to low risk), had an IQ of 46.5, and had an ICAP Service Level score of 59.9 (Level 3 – regular personal care and/or close supervision).

Why did people return to a SODC and did they receive TA from July 1, 2016 through December 31, 2018?

- Of the 190 transitions from a SODC to a non-SODC setting, 37 returned to a SODC (19.5%). Most (41.0%) returned for behavioral reasons, followed by short-term therapy (27%), other (24%), and medical (5%); 3% were missing a reason for return.
- Technical Assistance (TA) was provided to the majority of people who returned for a behavioral reason (12 of the 15 received TA: 11 received only behavioral TA and one received both behavioral and medical TA). TA was not provided for any of those that returned for a medical reason or another reason. Only one received TA (behavioral) upon their return from short-term therapy.
- Of the 13 people who returned to a SODC from a CILA, all did so because of a behavioral reason.

How do the demographics and characteristics of persons who transitioned compare across residential settings from July 1, 2016 through December 31, 2018?

- Those transitioning to community settings (CILA and family settings), were generally younger (CILA: 41.1 mean age, family: 32.0 mean age).

- People in community settings (CILA and family settings) had lower health risks, especially compared to those in institutional settings like ICF/DDs, SNFs, and SODCs. People transitioning to SNFs had the highest health risks (HRST score of 4.5 out of 6).
- People who had been in SODCs the longest generally transferred to institutional settings including ICF/DDs and SNFs.

What are the demographics and characteristics of people who died since transitioning from a SODC from July 1, 2016 through December 31, 2018?

- A total of 63 people died at a SODC (41) or after they transitioned out of a SODC (22 people).
- Individuals who died in an “Other” setting had the highest health risk and the lowest IQ.
- People who died at a SODC had a mean age of 64.1 years, a HRST of 4.5 (high moderate to high health risk) and had been in the SODC for an average of 23.3 years. They also had an ICAP Service Level score of 31.8 (Level 2 – Extensive personal care and/or constant supervision). All had an ID, 31.7% had a psychiatric disorder, and 7.3% had an ASD diagnosis.

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 between July 1, 2016 and December 31, 2018?

- 25 people (representing 28 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 58.2 years of age with an average length of stay in a SODC of 19.1 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 25.1 which indicates total personal care needs and a mean IQ of 18.2.
- These individuals had significant health and support needs.

Themes

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

- ❖ **Changing demographics and characteristics of the people transitioning:**
 - The percentage of live transitions to CILAs increased each year, beginning with 28.2% in FY2017 and ending with 40.5% in FY2019.
 - On average, most of those who transitioned were white, yet in FY2019, the majority of those who transitioned were non-White (54.8%).
 - The average age of those who transitioned decreased across the three years, starting with 49.5 years in FY2017 and ends with 42.9 years in FY2019.
 - Those with family guardians decreased each year, beginning with 60% in FY2017 and ending with 42.9% in FY2019
 - Overall, the greatest percentage of individuals who transitioned across FY2017-FY2019 were in the ICAP Service Level 4 category, though the greatest percentage

category was Level 1 in FY2017, Level 3 in FY2018, and then Level 4 in FY2019. Level 1 is total personal care needs and Level 4 is limited personal care needs.

- Mean HRST decreased over the three years, beginning with 3.0 in FY2017 and ending with 2.5 in FY2019. The percentage of people in the high risk HRST group (HRST \geq 4) also decreased over the years.
- The mean age of those who transitioned to CILAs and remained in them after their transition decreased over the three years (FY2017: 49, FY2019: 40.2); mean IQ decreased, HRST remained stable.

❖ **Challenges in community settings for people with ID and a psychiatric diagnosis.**

- The majority of those who transitioned out of SODCs had a psychiatric diagnosis (58%). The rate of transition for people with psychiatric diagnoses increased from FY2017 to FY2018 (from 49.3% to 67.5%) but then decreased again in FY2019 (54.8%) though it's important to reiterate that FY2019 only contains six months of data.
- All of those that returned to a SODC from a CILA did so for behavioral reasons.
- While most of the 15 people who returned to a SODC for a behavioral reason received technical assistance, three people (20%) returned before they were able to receive technical assistance.

These themes are difficult to interpret without additional affirmation and research. However, they suggest the lack of capacity in the community to be able to receive additional transitions, especially from people with psychiatric diagnoses. The budget challenges that the state of Illinois has faced since FY2016, and even before, continue to have lasting impacts on services for people with intellectual and developmental disabilities (IDD). Providers continue to experience difficulty in providing services to consumers with IDD in the community with persistent barriers like a low supply of direct support workers and the new barriers like the restructuring of independent supports coordinators (ISCs) in the state. The impact of the Home and Community-Based Services Final Rule which requires providers receiving waiver funds to adhere to particular guidelines for community settings will also undoubtedly impact the ability of providers to support people with IDD within the community, possibly making it more difficult to deliver services though perhaps better for consumers in the long-run.

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

There were noticeable differences in a few outcomes from the previous report (FY2013-FY2016) observed in the current report. For instance, a lower percentage of people transitioned to a CILA in FY2017-FY2019 (31.4%) compared to those transitioning between FY2013-FY2016 (49.9%). Simultaneously, the number of people who were discharged to SNF doubled from 12.3% during FY2013-FY2016 to 26.6% between FY2017 and FY2019. However, those who remained in their discharge setting continuously increased between FY2017-FY2019 (from 28.1% during FY2013-FY2016 to 47.8%) and this was especially pronounced in those who went

to CILAs (72% continuous placement in FY2017-FY2019 vs. 45% in FY2013-FY2016). However, there was a greater percentage of returns to a SODC during FY2017-FY2016.

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 (e.g., Lulinski-Norris, 2014).

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. However, the Residential Information Systems Project report by Larson et al. (2018) shows that those in SODCs in Illinois (as of June 30, 2016) have a different distribution of the level of ID than those who left institutions in Illinois: those remaining in institutions were mostly those with profound ID (50%) compared to 33.5% of people who transitioned out of institutions shown in this report between July 1, 2016 and December 31, 2018. Including this data in the next evaluation would add to the usefulness of the results.

Commented [CC1]: Added this paragraph. Feel free to move it somewhere that you think is more appropriate.

Commented [CC2]: Added this sentence.

References

- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *State of the states in intellectual and developmental disabilities: Emerging from the Great Recession*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Braddock, D., Hemp, R. E., Tanis, E. S., Wu, J., & Haffer, L. (2017). *The state of the states in developmental disabilities* (11 ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Chowdhury, M., & Benson, B. A. (2011). Deinstitutionalization and quality of life of individuals with intellectual disability: A review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities*, 8(4), 256-265. doi:10.1111/j.1741-1130.2011.00325.x
- Heller, T., Schindler, A., & Rizzolo, M. C. (2008). *Review of outcomes studies on community placements [Unpublished Technical Report]*. Chicago, IL: University of Illinois at Chicago.
- Kaiser Commission on Medicaid and the Uninsured. (2004). *Olmstead v. L.C.: The interaction of the Americans with Disabilities Act and Medicaid*. Retrieved from <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/olmstead-v-l-c-the-interaction-of-the-americans-with-disabilities-act-and-medicaid.pdf>
- Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Journal on Intellectual and Developmental Disabilities*, 114(3), 193-222. doi:10.1352/1944-7558-114.3.193
- Lakin, C., Larson, S., & Kim, S. (2011). *Behavioral outcomes of deinstitutionalization for people with intellectual and/or developmental disabilities: Third decennial review of U.S. studies, 1977-2010*. Retrieved from <https://ici.umn.edu/products/prb/212/default.html>
- Larson, S. A., Eschenbacher, H. J., Anderson, L. L., Taylor, B., Pettingell, S., Hewitt, A., . . . Bourne, M. L. (2018). *In-home & residential supports for persons with intellectual or developmental disabilities: Status and trends through 2016*. Retrieved from https://risp.umn.edu/sites/risp.umn.edu/files/2018-07/RISP2016_WEB.pdf
- Lulinski-Norris, A. (2014). *Community Capacity to Provide Mental/Behavioral Health Services to People with Developmental Disabilities* (Doctoral dissertation). Chicago, IL.
- Lulinski-Norris, A., Rizzolo, M. C., & Heller, T. (2010). *An Analysis of Movement from State Operated Developmental Centers in Illinois*. Chicago, IL: Institute on Disability and Human Development, University of Illinois at Chicago.
- Lulinski-Norris, A., Rizzolo, M. C., & Heller, T. (2012). *An Analysis of Movement from State Operated Developmental Centers in Illinois: FY2009 Update*. Chicago, IL: Institute on Disability and Human Development, University of Illinois at Chicago.
- Owen, R., Crabb, C., & Langi, F. L. (2017). *An Analysis of Movement from State-Operated Developmental Centers: Transitions between January 1, 2013 – June 30, 2016*.

Chicago, IL: Institute on Disability and Human Development, University of Illinois at Chicago.

- Rizzolo, M. K., Larson, S. A., & Hewitt, A. S. (2016). Long-term supports and services for people with IDD: Research, practice, and policy implications. In *Critical Issues in Intellectual and Developmental Disabilities: Contemporary Research, Practice, and Policy*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Scott, N., Lakin, K. C., & Larson, S. A. (2008). The 40th anniversary of deinstitutionalization in the United States: Decreasing state institutional populations, 1967–2007. *Intellectual and Developmental Disabilities, 46*(5), 402-405. doi:10.1352/2008.46:402-405
- Stancliffe, R. J., & Lakin, K. C. (2006). Longitudinal frequency and stability of family contact in institutional and community living. *Mental Retardation, 44*(6), 418-429. doi:10.1352/0047-6765(2006)44[418:LFASOF]2.0.CO;2
- Vasudevan, V., Rizzolo, M. C., Heller, T., & Lulinski, A. (2015). *An Analysis of Movement from Illinois State-Operated Developmental Centers: FY2010-2012 Update*. Chicago, IL: Institute on Disability and Human Development, University of Illinois at Chicago.