An Analysis of Movement from Illinois State-Operated Developmental Centers: Transitions between July 1, 2016- June 30, 2020

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August 2021

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 Melissa Shaw for coordinating the data collection and serving as the main contact for the evaluation team.

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Suggested Citation

Crabb, C., Hsieh, K., & Heller, T. (2021). *An Analysis of Movement from Illinois State-Operated Developmental Centers: Transitions between July 1, 2016 – June 30, 2020*. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

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Acronyms

ASD: Autism spectrum disorder

CILA: Community Integrated Living Arrangement

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

HRST: Health Risk Screening Tool

ICAP: Inventory for Client and Agency Planning

ICF/DD: Intermediate Care Facility for Developmental Disabilities

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, 2020. 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), from January 1, 2013 through June 30, 2016 (Owen, Crabb, & Langi, 2017), and from July 1, 2016 through December 31, 2018 (Crabb, Hsieh, & Heller, 2020) 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 July 2021.

Findings

How many individuals transitioned out of Illinois SODCs?

- There were 342 live transitions out of SODCs in this timeframe. The number of transitions was highest in FY2019 (92) and lowest in FY2017 (78).
- The 342 live transitions represent 325 people, 15 who transitioned twice and one who transitioned three times.
- There were also a total of 127 deaths within SODC or post transitions because the person died within the SODC (82) or in their discharge setting (45) post-transition.

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 44.2 years of age, and the majority (75.4%) were male. Slightly less than half of people who transitioned had family members as their guardian (49.2%), while 27.7% had a public guardian. On average, people who transitioned had lived in the SODC for 12.2 years, ranging from several days to nearly 52 years. Most people who transitioned were White (66.2%), though this percentage decreased from 76.6% in FY2018 to 60.0% in FY2020.
- Nearly two-thirds (61.8%) of people who transitioned had at least one psychiatric diagnosis. The most common psychiatric diagnoses were mood disorder (29.5%) and psychotic disorder (20.9%). In addition to psychiatric diagnoses, 11.7% of people who transitioned were diagnosed with autism spectrum disorder (ASD) and 3.4% were diagnosed with Pervasive Developmental Disorder (PDD).
- People who transitioned had varying levels of intellectual disability (ID). Over one third had mild ID (37.2%). People who transitioned had an average Inventory for Client and Agency Planning (ICAP) Service Level score of 54.8, 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 about quarter (27.7%) 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.

To what type of residential setting did individuals transition?

- Of the 342 live transitions, slightly less than a third (31.6%) went to CILAs, or Community Integrated Living Arrangements (both Intermittent CILA, or I-CILA, and 24-hour CILA), 22.5% went to skilled nursing facilities (SNFs), 11.1% went to another SODC, 9.1% went to jail, 8.8% went to family settings, 5.6% went to an Intermediate Care Facility for Developmental Disabilities (ICF/DD), 5.3% went to a mental health center (MHC), and 6.1% went to another setting.
- The percentage of transitions to an ICF/DD (10.3% vs. 3.5%) and a SNF (24.4% vs. 9.4%) decreased from FY2017 to FY2020.
- However, the percentage of transitions to other SODCs (9% vs.18.8%) and family homes (7.7% vs.16.5%) increased two fold fromFY2017 to FY2020.

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

- SODC staff follow-up with people who have transitioned for 12 months; because of those who transitioned more than a year ago, 13.7% have a current status of unknown. Among those individuals whose data was available, 44.7% of transitions had a continuous placement, meaning that they were still in the setting that they transitioned to out of a SODC originally. 22.2% returned to a SODC and 13.7% died.
- Of the 107 transitions that went to a CILA and who had a current status, over two-thirds remained in the same setting and with the same service provider (continuous placement), while 1.9% remained with the same provider but in a different residence in the community, and 6.5% remained in the community but in a different resident and with another provider. Only 1.9% of people who transitioned to a CILA died and 19.6% returned to a SODC.
- People who originally transitioned to a CILA (24-hour CILA or I-CILA) and remained in a CILA, either with the same provider or another and either in the original residence or another one, were middle-aged (41.5 years on average), had an average HRST score of 1.9 (lowest to low risk), had an average IQ of 47.8, and had an average ICAP Service Level score of 62.2 (Level 3 – regular personal care and/or close supervision).

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

- Of the 304 transitions from a SODC to a non-SODC setting, 62 returned to a SODC (20.4%). The main reason for return (for those that were not missing a return reason) was behavioral (37.7%), followed by short-term therapy (24.6%), other (23.0%), and medical (14.8%).
- Technical assistance (TA) was provided to 87% of returns for a behavioral reason (behavioral TA). TA was provided to one person (out of nine, 11.1%) that returned for a

medical reason (behavioral TA). Of those returning for another reason or for short-term therapy, one (3.4%) received TA.

- Of the returns 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?

- Those transitioning to community settings (CILA and family settings), were generally younger (24-hour CILA: 40.5 mean age, I-CILA: 41.4 mean age, and family: 34.8 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.

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

- A total of 127 people died at a SODC (82) or after they transitioned out of a SODC (45). Of the 45 who died post-transition, 13 were missing their post-transition setting (28.9%) and 32 died in another setting (71.1%).
- People who died at a SODC had a mean age of 65.1 years, a mean HRST of 4.1 (high moderate to high health risk), and had been in the SODC for an average of 25.3 years. They also had an average ICAP Service Level score of 30.8, a score within Level 2 which represents the second most extensive support needs. 42.7% had at least one psychiatric disorder, and 11.0% 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 need 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, and had the highest ICAP Service Level score (less supports needed), lowest health risk, and highest IQ compared to both those who died in SODCs and other settings.

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

- 30 people (representing 35 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 59.3 years of age with an average length of stay (LOS) in a SODC of 18.7 years. Additionally, they had a mean HRST score of 4.4 out of 6 indicating a high moderate to high health risk. Their mean ICAP Service Level score was 26.7 which indicates the highest level of support needs and had a mean IQ of 18.3.

- These individuals had significant health and personal support needs.

Themes

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

- Changing demographics and characteristics of the people transitioning:
  - Most people who transitioned were White (66.2%),
  - On average and for each individual fiscal year, most of those who transitioned were White, yet this percentage decreased from 76.6% in FY2018 to 60.0% in FY2020.
  - Those with family guardians decreased between FY2017 and FY2020, beginning with 60.3% and ending with 43.5%.
  - The percentage of people who had a profound disability decreased each fiscal year, beginning with 39.7% in FY2017 and ending with 17.6% in FY2020. The portion of mild ID increased from 34.2% in FY2017 to 43.5% in FY2020.
  - Mean Health Risk Screening Tool (HRST) score decreased each fiscal year and the percentage of people in the high risk HRST group (HRST ≥ 4) decreased by almost 15.4% across the four fiscal years.
  - The frequency of return to a SODC from a non-SODC setting increased sharply from FY2017 through FY2019, but then went down again in FY2020.
- Increasing challenges in community settings with an increased number of people with ID and a psychiatric diagnosis:
  - The majority of those who transitioned out of SODCs had a psychiatric diagnosis (61.8%). The percentage of people transitioning with a psychiatric diagnosis increased from FY2017 to FY2020 (from 47.9% to 71.8%). The percentage of people who transitioned with a mood disorder increased by 13.6 percentage points from FY2017 to FY2020, and the frequency of personality disorders increased by 6.5 percentage points from FY2017 to FY2020.
  - All the individuals who returned to a SODC from a CILA did so for behavioral reasons.

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, 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 of support needs. The *State of the States in Developmental Disabilities* project tracks state spending on people with IDD in community settings and in SODCs. 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, 2017, 119 institutions were open across the United States compared to 376 between 1960 and 2017 (Larson et al., 2020).

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 FY2020, 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 & Heller, 2021; 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 2020 (Crabb et al., 2020) and in the summer of 2021, the Illinois Department of Human Services, Division of Developmental Disabilities (DHS-DDD) extended the database to include transitions from January 1, 2019 through June 30, 2020. 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 Illinois policymakers about the

transitions out of the SODCs to improve transition planning in the future. All data in this report are from July 1, 2016 to June 30, 2020.

The questions that this report answers, for the time period of July 1, 2016 – June 30, 2020, 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 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, 2020 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), and July 1, 2016 – December 31, 2018 (Crabb et al., 2020).

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 July 2021:

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

Data was coded and then analyzed using SPSS Statistics 24.0 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, 2020. Some tables are broken out by Fiscal Year (FY).

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

There were a total of 342 live transitions out of the Illinois SODC system during the entire time period. These transitions represented 325 people, as 309 people transitioned only once, 15 people transitioned twice, and one person transitioned three times during the time period. Questions one through six focus on these 342 live transitions representing 325 people, while question seven focuses on transitions from SODCs where the person died in the SODC during this period (82 people) and on people who died in their transition setting following discharge (45 people) from a SODC. Question eight focuses on 30 people (representing 35 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, in terms of the number of live transitions, FY2019 represented the largest percentage of transitions, accounting for 26.9% of the total transitions and FY2017 represented the smallest percentage of total transitions (22.8%). The Choate Developmental Center (Choate) accounted for the most transitions over this period (138, 40.4%). The second highest number of transitions were from Governor Samuel H. Shapiro Developmental Center (Shapiro) with 95 (27.8%) transitions. Together, Choate and Shapiro accounted for over two thirds of the total transitions from SODCs in Illinois. Ludeman Developmental Center (Ludeman) transitioned 14.9% 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 1.2% and 8.5% of the total transitions.

Table 1: SODC Transitions by Fiscal Year

SODC	FY2017	FY2018	FY2019	FY2020	FY2017-FY2020	% of Total by SODC
Choate	33	30	45	30	138	**40.4%**
Fox	3	0	0	1	4	**1.2%**
Kiley	6	8	7	8	29	**8.5%**
Ludeman	8	14	11	18	51	**14.9%**
Mabley	0	2	1	4	7	**2.0%**
Murray	6	3	5	4	18	**5.3%**
Shapiro	22	30	23	20	95	**27.8%**
Total	78	87	92	85	342	
% of Total for FY	**22.8%**	**25.4%**	**26.9%**	**24.9%**		

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

Table 3 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 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 live transition was used to calculate demographics. The research team only had access to data on people who transitioned, so we cannot determine whether or not these characteristics are statistically different from the characteristics of the SODC population as a whole.

Age

Age was calculated from the time of discharge. Of the 325 individuals who transitioned out of the seven Illinois SODCs during the study period, the youngest was 18 years and the oldest was 94. The average age was 44.2 (SD = 17.5) years at the time of transition. The average age significantly decreased across four fiscal years (p=0.029); it decreased from FY2017 (49.8) to FY2020 (37.2).

Length of Stay (LOS)

People who transitioned out of a SODC during the study period had lived in the SODC for an average of 12.2 years, ranging from several days to nearly 52 years (SD = 14.7).

Gender

Across all four fiscal years, most of the individuals who transitioned out of the SODCs were male (75.4%); the percentage of males was the highest during FY2017 transitions (80.8%) and lowest during FY2019 transitions (72.2%).

Race

Across FY2017-FY2020, most people who transitioned out of SODCs were White (66.2%): this percentage decreased from FY2018 to FY2020 (from 76.6% to 60.0%, respectively).

Guardianship Status

Slightly less than half of the individuals who transitioned out of SODCs during the study period had family members as their guardians (49.2%). About a third of the 325 individuals that transitioned had a public guardian (90, 27.7%) and about a fifth were their own guardian, or deemed legally competent (70, 21.5%).

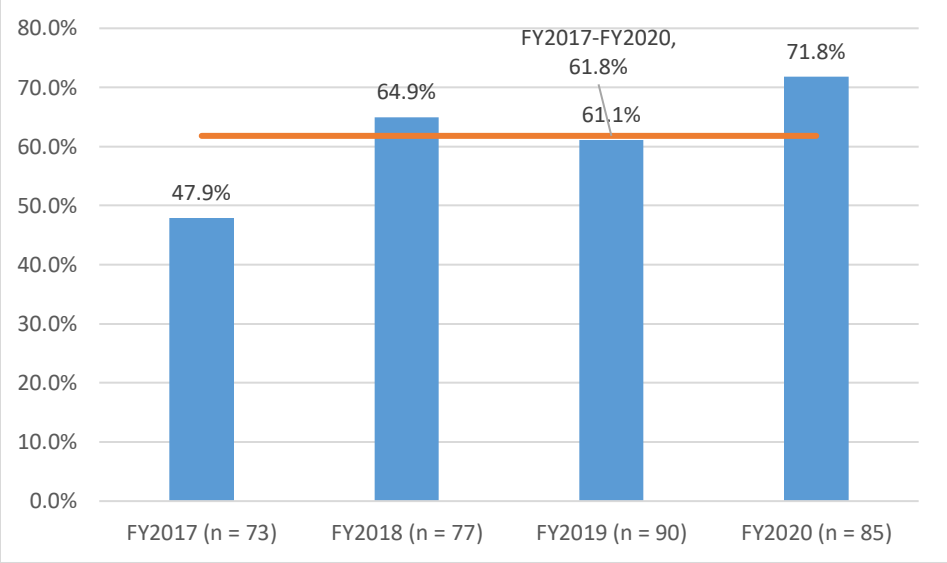
Table 2: Demographics by Fiscal Year

	FY2017 (n = 73)		FY2018 (n = 77)		FY2019 (n = 90)		FY2020 (n = 85)		FY2017-FY2020 (n = 325)	
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Age	49.8	17.1	47.5	19.6	43.5	16.0	37.2	15.1	44.2	17.5
LOS	13.4	14.9	13.8	16.5	12.1	14.6	9.6	12.7	12.2	14.7
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Gender										
Male	59	80.8%	57	74.0%	65	72.2%	64	75.3%	245	75.4%
Female	14	19.2%	20	26.0%	25	27.8%	21	24.7%	80	24.6%
Race										
White	48	65.8%	59	76.6%	57	63.3%	51	60.0%	215	66.2%
Non-White	25	34.2%	18	23.4%	33	36.7%	34	40.0%	110	33.8%
Guardianship										
Own	15	20.5%	18	23.4%	18	20.0%	19	22.4%	70	21.5%
Public	14	19.2%	21	27.3%	28	31.1%	27	31.8%	90	27.7%
Family	44	60.3%	37	48.1%	42	46.7%	37	43.5%	160	49.2%
Non-Family	0	0.0%	1	1.3%	1	1.1%	2	2.4%	4	1.2%
Unknown	0	0.0%	0	0.0%	1	1.1%	0	0.0%	1	0.3%

Psychiatric Diagnosis

Of the 325 individuals who transitioned, 201 people (61.8%) had at least one psychiatric diagnosis. Figure 1 illustrates the percentages of those transitioning across the entire time frame with a diagnosed psychiatric disorder. The percentage of people transitioning with a psychiatric diagnosis increased from FY2017 to FY2020 (from 47.9% to 71.8%).

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



Error! Not a valid bookmark self-reference. describes the percentage of individuals diagnosed with a psychiatric disorder by fiscal year. Over the course of the four fiscal years, the majority had a psychiatric diagnosis (61.8%); over a third had one psychiatric diagnosis (35.4%) and 26.4% had two or more psychiatric diagnoses. The most common psychiatric diagnoses were mood disorder (29.5%), psychotic disorder (20.9%), impulse control disorder (10.8%), childhood disorders (10.2%), personality disorders (8.3%), and anxiety disorders (7.7%).

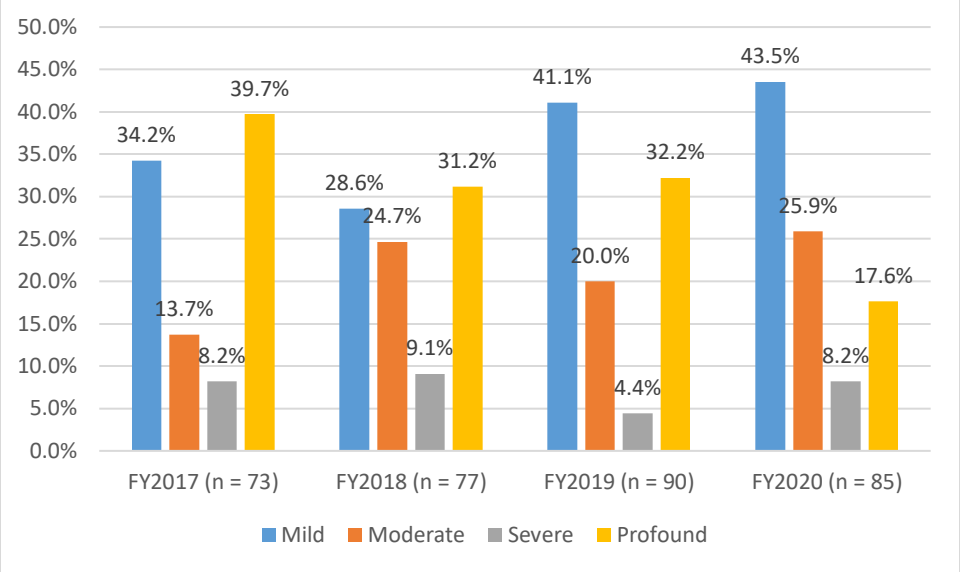
Table 3: Psychiatric Diagnosis by Fiscal Year

	FY2017 (n = 73)		FY2018 (n = 77)		FY2019 (n = 90)		FY2020 (n = 85)		FY2017-FY2020 (n = 325)	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Number of psychiatric diagnoses										
0	38	52.1%	27	35.1%	35	38.9%	24	28.2%	124	38.2%
1	18	24.7%	33	42.9%	31	34.4%	33	38.8%	115	35.4%
2	11	15.1%	13	16.9%	13	14.4%	19	22.4%	56	17.2%
3	6	8.2%	3	3.9%	8	8.9%	9	10.6%	26	8.0%
4	0	0.0%	1	1.3%	3	3.3%	0	0.0%	4	1.2%
Psychiatric diagnosis*										
Psychotic	15	20.5%	17	22.1%	16	17.8%	20	23.5%	68	20.9%
Impulse	9	12.3%	5	6.5%	11	12.2%	10	11.8%	35	10.8%
Anxiety	4	5.5%	5	6.5%	8	8.9%	8	9.4%	25	7.7%
Mood	15	20.5%	28	36.4%	24	26.7%	29	34.1%	96	29.5%
Sexual	0	0.0%	0	0.0%	1	1.1%	2	2.4%	3	0.9%
Personality	3	4.1%	5	6.5%	10	11.1%	9	10.6%	27	8.3%
Childhood	6	8.2%	7	9.1%	11	12.2%	9	10.6%	33	10.2%
Substance	0	0.0%	2	2.6%	1	1.1%	0	0.0%	3	0.9%
Adjustment	1	1.4%	0	0.0%	1	1.1%	1	1.2%	3	0.9%
***Not mutually exclusive**										

Level of Intellectual Disability (ID)

Of the 325 individuals who transitioned out of a SODC across the entire time frame, all but one (0.3%) had a diagnosis of ID. Figure 2 illustrates the level of ID by fiscal year. Over one third (37.2%) of those who transitioned during the time period had a mild ID, with an increase from 34.2% in FY2017 to 43.5% in FY2020. Profound was the next highest category across the entire study period (29.8%) though this percentage decreased from FY2017 (39.7%) to FY2020 (17.6%).

Figure 2: Level of ID by Fiscal Year



Autism Spectrum Disorder (ASD) Diagnosis

Over the course of four fiscal years, 11.7% of people who transitioned had a diagnosis of autism spectrum disorder (ASD) while 3.4% 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

ASD Dx	FY2017 (n = 73)		FY2018 (n = 77)		FY2019 (n = 90)		FY2020 (n = 85)		FY2017-FY2020 (n = 325)	
	n	%	n	%	n	%	n	%	n	%
No ASD Dx	67	91.8%	65	84.4%	76	84.4%	68	80.0%	276	84.9%
ASD	3	4.1%	8	10.4%	11	12.2%	16	18.8%	38	11.7%
PDD	3	4.1%	4	5.2%	3	3.3%	1	1.2%	11	3.4%

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

The lowest ICAP Adaptive Behavior Domain score was in the area of Motor Skills (435.5) while the highest was in the area of Personal Living (470.9). 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. These scores indicate deficits in each area of Adaptive Behavior. A trend analysis indicates each adaptive area mean score increased across time (p value ranges from 0.02-0.002).

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

Adaptive Area	FY2017 (n = 73)	FY2018 (n = 75)	FY2019 (n = 89)	FY2020 (n = 85)	FY2017-FY2020 (n = 322)
Motor Skills	419.3	432.9	434.7	452.4	435.5
Social & Communication Skills	440.4	450.8	452.8	468.2	453.6
Personal Living	459.2	468.8	471.4	482.4	470.9
Community Living	438.3	452.7	454.8	466.4	453.6
Broad Independence	438.6	451.4	454.5	467.2	453.5

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 the table below.

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

The range of ICAP Service Level Scores during the study period was 2 - 95. The average ICAP Service Level Score for individuals who transitioned was 54.8 (SD = 22.8), which indicates an average need (Level 3) for regular personal care and close supervision. A trend analysis indicates the mean ICAP service level score increased across time (P=0.003). Table 6 describes the average, minimum, and maximum ICAP Service Level Scores by fiscal year and for the entire study period.

Table 6: ICAP Service Level Scores by Fiscal Year

	FY2017 (n = 73)	FY2018 (n = 75)	FY2019 (n = 89)	FY2020 (n = 85)	FY2017- FY2020 (n = 322)
Minimum	9	13	5	2	2
Mean	50.5	53.3	54.8	59.84	54.8
Maximum	95	94	88	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. Overall, the Maladaptive Behavior General Score was the lowest (-11.7) while the Internalized score was the highest (-6.7). Maladaptive Behavior Domain scores range from +10 to -41 and below. 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 four fiscal years in the means of internalized, social and general maladaptive scores were detected. There was a significant trend (P =0.019) of the lower mean externalized maladaptive score representing an increased frequency/severity of problem behaviors of being hurtful to others, destructive to property, or engaging in disruptive behavior across the four fiscal years.

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

Maladaptive Area	FY2017 (n = 73)	FY2018 (n = 75)	FY2019 (n = 89)	FY2020 (n = 85)	FY2017-FY2020 (n = 322)
Internalized	-5.2	-8.5	-5.9	-7.4	-6.7
Asocial	-8.8	-10.8	-11.0	-11.4	-10.6
Externalized	-4.7	-8.8	-8.3	-9.4	-7.9
General	-9.0	-12.8	-11.8	-12.9	-11.7

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 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

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. 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. The percentage of people in the high to highest HRST score group was highest in FY2017 (34.2%) with a mean HRST of 3.0 (moderate risk level) and lowest in FY2020 (18.8%) with a mean HRST of 2.3 (low to moderate risk level).

Table 8: HRST Health Risk Levels

HRST	FY2017 (n = 73)	FY2018 (n = 77)	FY2019 (n = 90)	FY2020 (n = 85)	FY2017-FY2020 (n = 325)
% High HRST (≥ 4)	34.2%	31.2%	27.8%	18.8%	27.7%
Mean HRST	3.0	3.0	2.6	2.3	2.7

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

Error! Reference source not found. describes the percentage of transitions (n = 342) from each SODC to various types of residential settings between July 1, 2016 and June 30, 2020. 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 (31.6%) of the 342 transitions during the entire time period. The second most common post-transition setting was a skilled nursing facility (SNF), which made up 22.5% of the transitions during the time period. Approximately 11.1% of transitions went to another SODC, followed by 9.1% of transitions to jail; 8.8% went to family settings, 5.6% went to an Intermediate Care Facility for Developmental Disabilities (ICF/DD), and 5.3% went to a State-Operated Mental Health Center (MHC). The remaining 6.1% transitioned to other settings. Mabley had the highest percent of transitions that went to CILAs (57.1%) while Fox had no transitions to CILAs, though Fox only had four transitions out during the study period.

Table 9: Discharge Setting by SODC Discharged From

Setting	Choate (n = 138)	Fox (n = 4)	Kiley (n = 29)	Ludeman (n = 51)	Mabley (n = 7)	Murray (n = 18)	Shapiro (n = 95)	Total (n = 342)
CILA	37.0%	0.0%	27.6%	17.6%	57.1%	22.2%	28.4%	30.1%
I-CILA	0.0%	0.0%	17.2%	0.0%	0.0%	0.0%	0.0%	1.5%
ICF/DD	2.9%	75.0%	0.0%	9.8%	28.6%	5.6%	4.2%	5.6%
Other SODC	9.4%	0.0%	0.0%	23.5%	0.0%	22.2%	9.5%	11.1%
MHC	8.0%	0.0%	6.9%	9.8%	0.0%	0.0%	0.0%	5.3%
SNF	0.0%	0.0%	31.0%	33.3%	0.0%	22.2%	49.5%	22.5%
Jail	22.5%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	9.1%
Family	11.6%	0.0%	3.4%	2.0%	14.3%	27.8%	6.3%	8.8%
Other	8.7%	25.0%	13.8%	3.9%	0.0%	0.0%	2.1%	6.1%

Table 10 illustrates the transition settings by fiscal year. The percentage of transitions to CILAs was highest in FY2019 (35.9%) and then decreased 10.0% in FY2020 (25.9%). The percentage of transitions to an ICF/DD (10.3% vs. 3.5%) and a SNF (24.4% vs. 9.4%) decreased from FY2017 to FY2020. However, the percentage of transitions to other SODCs (9% vs.18.8%) and family homes (7.7% vs. 16.5%) increased two-fold from FY2017 to FY2020.

Table 10: Discharge Settings by Fiscal Year

Setting	FY2017 (n = 78)	FY2018 (n = 87)	FY2019 (n = 92)	FY2020 (n = 85)	FY2017-FY2020 (n = 342)
CILA	28.2%	29.9%	35.9%	25.9%	30.1%
I-CILA	0.0%	0.0%	1.1%	4.7%	1.5%
ICF/DD	10.3%	6.9%	2.2%	3.5%	5.6%
Other SODC	9.0%	4.6%	12.0%	18.8%	11.1%
MHC	1.3%	8.0%	6.5%	4.7%	5.3%
SNF	24.4%	32.2%	23.9%	9.4%	22.5%
Jail	10.3%	9.2%	6.5%	10.6%	9.1%
Family	7.7%	4.6%	6.5%	16.5%	8.8%
Other	9.0%	4.6%	5.4%	5.9%	6.1%

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

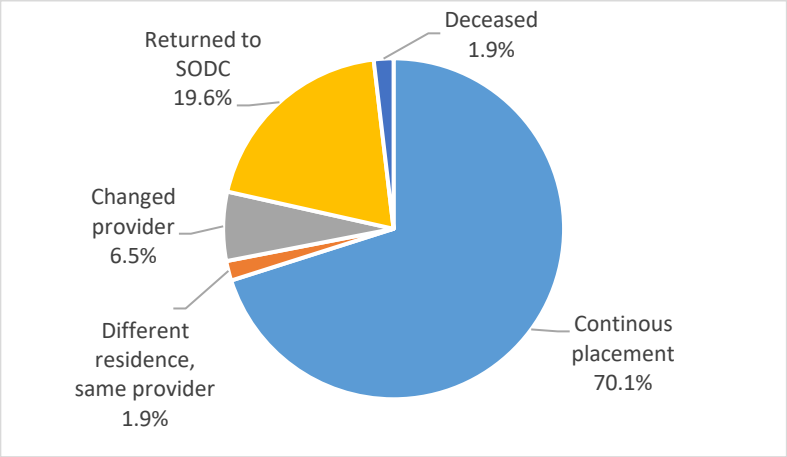
Regulations only require the Department of Human Services follow individuals for one year after they transitioned. Because data for this report covers July 1, 2016 – June 30, 2020, the SODCs from which individuals transitioned were not required to track the current living situation of many of these individuals at the time data was provided (July 2021). As a result, the current status of 13.7% of the transitions during this period are unknown and 0.6% are missing. Of those for whom data was available, 44.7% had maintained a continuous placement in their new setting following that transition.

Table 11: Current Status of Transitioned Individuals by Fiscal Year

Current Status	FY2017 (n = 78)	FY2018 (n = 87)	FY2019 (n = 92)	FY2020 (n = 85)	FY2017-FY2020 (n = 342)
Continuous placement	50.0%	41.4%	44.6%	43.5%	44.7%
Different residence, same provider	1.3%	0.0%	1.1%	1.2%	0.9%
Changed provider	1.3%	1.1%	2.2%	8.2%	3.2%
Returned to SODC	10.3%	33.3%	31.5%	11.8%	22.2%
Deceased	24.4%	11.5%	9.8%	10.6%	13.7%
Unknown	11.5%	12.6%	8.7%	22.4%	13.7%
MHC	0.0%	0.0%	2.2%	1.2%	0.9%
Missing	1.3%	0.0%	0.0%	1.2%	0.6%

Of the 107 transitions from a SODC to a CILA (24-hour or I-CILA) from July 1, 2016 through June 30, 2020 (Figure 3) with a current status, over three-quarters (70.1%) remained at the same home and with the same service provider. About a fifth of those discharged to CILAs returned to a SODC. Two moved residences but stayed with the same provider (1.9%) while 6.5% moved homes and switched providers. Two transitions discharged to a CILA died (1.9%).

Figure 3: Current Status of Transitions from a SODC to a CILA (n = 107)



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 41.5 years, mean HRST score of 1.9 (lowest to low health risk), mean IQ of 47.8, and a mean ICAP Service Level score of 62.2 indicating an average need (Level 3) for regular personal care and close supervision. There was a notable decline in mean age from FY2017 (mean= 49.0) to FY2020 (mean = 36.4), see Table 12.

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

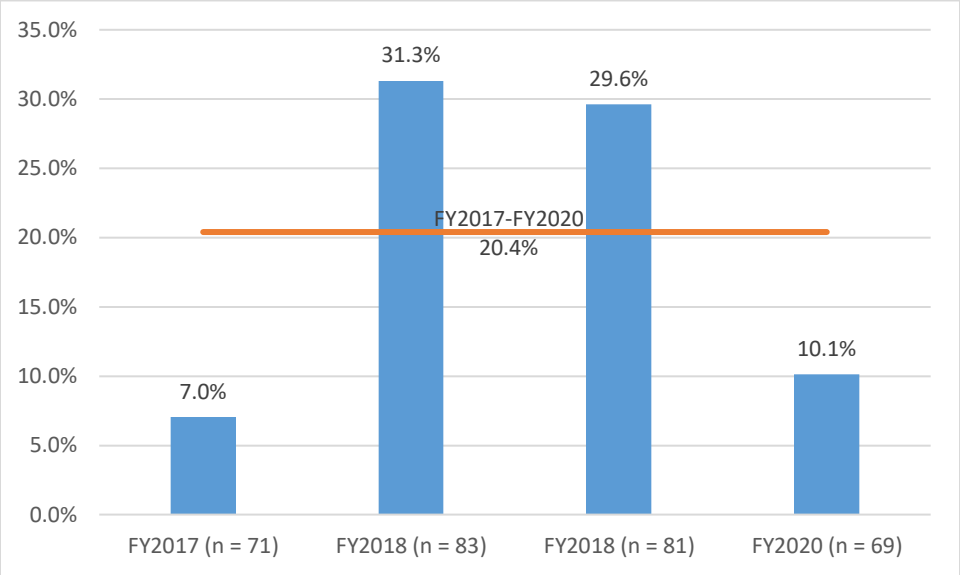
Characteristic	FY2017 (n = 18)	FY2018 (n = 18)	FY2019 (n = 26)	FY2020 (n = 22)	FY2017-FY2020 (n = 84)
Age (years)	49.0	41.0	40.9	36.4	41.5
HRST	1.8	1.8	2.0	1.9	1.9
IQ	52.7	43.5	43.7	52.3	47.8
ICAP Service Level	64.6	53.0	63.9	65.9	62.2

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

Between July 1, 2016 and June 30, 2020, of the 304 transitions from a SODC to a non-SODC setting, 62 ultimately returned to a SODC (20.4%). The percentage of those returning to a SODC rose sharply from FY2017 to FY2018 (7.0% to 31.3%) and then fell again in FY2020 to 10.1% (

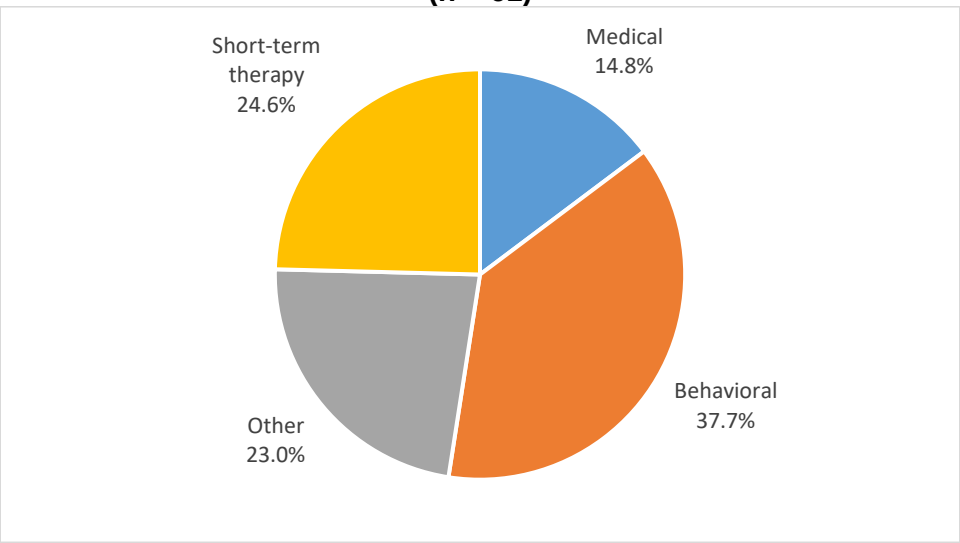
Figure 4).

Figure 4: Frequency of Return to a SODC from a Non-SODC Post-Transition Placement (n = 304)



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 61 returns to a SODC where the return reason was not missing, the main reason for return was behavioral (37.7%), followed by short-term therapy (24.6%), other (23.0%), and medical (14.8%), see Figure 5.

Figure 5: Reasons for Return to a SODC from a Non-SODC Post-Transition Setting (n = 61)



For the purposes of this report, 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 (24) and Shapiro (18) had the highest number of returns with 54.2% of those receiving TA at Choate and 27.8% receiving TA at Shapiro. Kiley had seven returns, two of which received TA (28.6%). Ludeman had 11 returns and one was provided with TA (9.1%). Of the two returns to Murray, one received TA.

Table 13: Receipt of TA for SODC Returners by Center

SODC	Number of Returns	Number Receiving TA	Percent Receiving TA
Choate	24	13	54.2%
Fox	0	-	-
Kiley	7	2	28.6%
Ludeman	11	1	9.1%
Mabley	0	-	-
Murray	2	1	50.0%
Shapiro	18	5	27.8%
Total	**62**	**22**	**35.5%**

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 nine transitions back to a SODC because of medical reasons, only one received TA (behavioral TA, 11.1%). Conversely, for those who returned to a SODC because of behavioral reasons, 82.6% received behavioral TA and one (4.3%) received medical and behavioral TA. Of the remaining 29 transitions (14 for other reasons and 15 due to a short-term therapy return), one received TA (behavioral TA, 3.4%).

Figure 6: Reason for Return to SODC from a Non-SODC Post-Transition Setting by TA Received

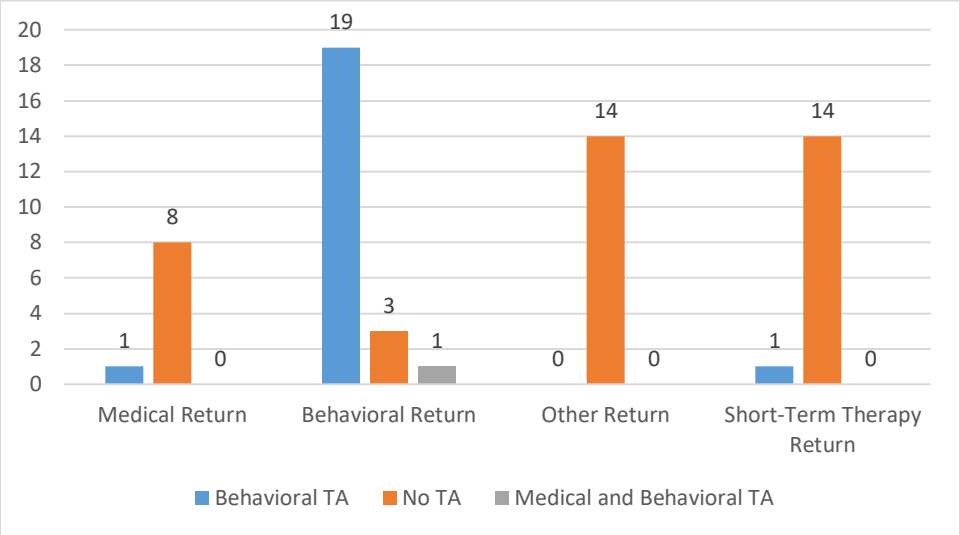


Table 14 compares the reason (medical, behavioral, other, and short-term therapy), for a return to a SODC by the setting from which they returned to the SODC. Those that returned from a CILA did so for behavioral reasons (100%). Of the 26 that returned to a SODC from a SNF, eight did so for medical reasons (30.8%), eight did so for short-term therapy (30.8%), and the other nine did so for another reason (34.6%).

Table 14: Reason for Return to a SODC by Non-SODC Post-Transition Placement

Reason for Return	24-Hour CILA (n = 21)	MHC (n = 8)	SNF (n = 26)	Jail (n = 3)	Family (n = 2)	Other (n = 2)
Medical	0 (0%)	0 (0%)	8 (30.8%)	0 (0%)	0 (0%)	1 (50%)
Behavioral	21 (100%)	0 (0%)	0 (0%)	0 (0%)	2 (100%)	0 (0%)
Other	0 (0%)	2 (25%)	9 (34.6%)	3 (100%)	0 (0%)	0 (0%)
Short-term therapy	0 (0%)	6 (75%)	8 (30.8%)	0 (0%)	0 (0%)	1 (50%)

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

For the individual 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 = 26.9) and those who went to a mental health center (mean age = 28.4). Those who transitioned to community settings, including CILAs and family settings, were also generally younger (40.5 mean age for 24-hour CILAs, 41.4 mean age for I-CILAs, and 34.8 mean age for family settings) than other transition settings, such as SNFs and ICF/DDs. 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 and the lowest IQs. People who had been in 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. People returning back to SODCs and those transitioning to MHCs had the highest percentage of having at least one psychiatric diagnosis. People transitioning out of SODCs and into I-CILAs had the highest percentage of an ASD diagnosis (60.0%).

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

	CILA (n = 99)	I-CILA (n = 5)	ICF/DD (n = 19)	SODC (n = 34)	MHC (n = 13)	SNF (n = 74)	Jail (n = 30)	Family (n = 30)	Other (n = 21)
	mean	**mean**	**mean**	**mean**	**mean**	**mean**	**mean**	**mean**	**mean**
Age	40.5	41.4	60.6	37.4	28.4	62.0	26.9	34.8	44.5
LOS	8.4	9.7	24.3	4.6	3.1	26.2	0.6	4.7	14.8
HRST	2.0	2.2	3.4	2.6	1.9	4.3	1.0	0	2.7
ICAP Service Level	63.3	46.0	34.1	52.5	67.1	36.7	76.7	62.3	53.3
IQ	48.7	46.0	19.3	46.8	60.3	20.1	65.4	48.4	41.0
Psych Dx	73.7%	0.0%	42.1%	85.3%	84.6%	44.6%	43.3%	73.3%	57.1%
ASD Dx	16.2%	60.0 %	21.1%	26.5%	0.0%	9.5%	10.0%	20.0%	9.5%

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

A total of 127 people died either at a SODC or after they had transitioned out of a SODC from July 1, 2016 to June 30, 2020. 82 people died in a SODC and 45 died elsewhere. About a quarter of these 45 deaths post-transition did not have a discharged to setting within the data (28.9%) while the remainder occurred at other settings (71.1%). Table 16 compares demographic characteristics of individuals who died (n = 127) across the settings. The majority of the 127 deaths occurred at a SODC (64.6%). Individuals that died in a SODC were older (mean age = 65.1 years), had a lower average ICAP service level score (30.8, indicating a higher level of support needed), and had a higher average health risk (mean HRST score = 4.1), compared to those who died in other settings or whose post-transition setting was missing. However, those who died in other settings (mean IQ =18.3) and in a SODC (mean IQ= 17.7) had a slightly though not significant lower average IQ than those who had missing data in their post-transition setting (mean IQ=23.2). 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, 8.7% of people who died had autism, which was higher for those who died in SODCs (11.0%) versus those who died in other settings (3.1%) or were missing their post-transition setting (7.7%).

Table 16: Characteristics of Individuals who Died Across Settings (n = 127)

Characteristic	Missing (n = 13)	SODC (n = 82)	Other (n = 32)	Total (n = 127)
	Mean	**Mean**	**Mean**	**Mean**
Age	58.6	65.1	59.7	63.1
LOS	27.6	25.3	26.3	25.8
HRST	3.5	4.1	3.6	3.9
ICAP Service Level	36.2	30.8	33.2	32.0
IQ	23.2	18.3	17.7	18.7
	%	**%**	**%**	**%**
Frequency of Psych Dx	46.2%	42.7%	53.1%	45.7%
Frequency of ASD	7.7%	11.0%	3.1%	8.7%

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 30 people (representing 35 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, 2020.

As there were three individuals who transitioned twice and one individual who transitioned three times 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 30 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 59.3 years and they had an average LOS in the SODC of 18.7 years. These individuals had a mean HRST score of 4.4 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 26.7, the highest level of support needs) and a mean IQ of 18.3. These numbers show that these individuals have extensive health and other support needs. 13 individuals (43.3%) had at least one psychiatric diagnosis and five (16.7%) were also diagnosed with ASD.

Table 17: Characteristics of Individuals who Transitioned to Short-Term Nursing Facilities (n = 30)

Characteristic	Mean	SD
Age (years)	59.3	9.7
LOS (years)	18.7	17.2
HRST	4.4	1.6
ICAP Service Level	26.7	17.6
IQ	18.3	15.5
	n	**%**
Frequency of Psych Dx	13	43.3%
Frequency of ASD	5	16.7%

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 SODCs?

- There were 342 live transitions out of SODCs in this timeframe. FY2019 represented the largest portion of the total transitions (92, 26,9%) which FY2017 represented the smallest portion of the total transitions (78, 22.8%).
- The 342 live transitions represent 325 people, 15 who transitioned twice and one who transitioned three times.
- There were also a total of 127 transitions because the person died within the SODC (82) or in their discharge setting (45) post-transition.

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 44.2 years of age, and three-quarters were male. Nearly half of people who transitioned had family members as their guardian (49.2%), while 27.7% had a public guardian, and 21.5% were legally competent. On average, people who transitioned had lived in the SODC for 12.2 years, ranging from several days to almost 52 years. Most people who transitioned were White (66.2%) though this percentage dropped from 76.6% in FY2018 to 60.0% in FY2020.
- Nearly two-thirds (61.8%) of people who transitioned had at least one psychiatric diagnosis. The most frequent psychiatric diagnoses were mood disorder (29.5%) and psychotic disorder (20.9%). In addition to psychiatric diagnoses, 11.7% of people who transitioned were diagnosed with ASD and 3.4% were diagnosed with PDD.
- People who transitioned had varying levels of ID. Over one third had a mild ID (37.2%). People who transitioned had an average ICAP Service Level score of 54.8, 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 HRST score of 2.7 (between low and moderate health risk) and over a quarter (27.7%) 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?

- Of the 342 live transitions, slightly less than a third (31.6%) went to CILAs, or Community Integrated Living Arrangements (both Intermittent CILA, or I-CILA, and 24-hour CILA), 22.5% went to skilled nursing facilities (SNFs), 11.1% went to another SODC, 9.1% went to jail, 8.8% went to family settings, 5.6% went to an Intermediate

Care Facility for Developmental Disabilities (ICF/DD), 5.3% went to a mental health center (MHC), and 6.1% went to another setting.

- The percentage of transitions to an ICF/DD (10.3% vs. 3.5%) and a SNF (24.4% vs. 9.4%) decreased from FY2017 to FY2020.
- However, the percentage of transitions to other SODCs (9% vs.18.8%) and family homes (7.7% vs. 16.5%) increased two fold from FY2017 to FY2020.

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

- SODC staff follow-up with people who have transitioned for 12 months; because of those who transitioned more than a year ago, 13.7% have an unknown current status. For those whom data was available, 44.7% of transitions had a continuous placement, meaning that they were still in the setting that they transitioned to out of the SODC originally. 22.2% returned to a SODC and 13.7% died.
- Of the 107 transitions that went to a CILA and who had a current status, over two-thirds remained in the same setting and with the same service provider, while 1.9% remained with the same provider but in a different residence in the community and 6.5% remained in the community but with another provider and in a different residence. Only 1.9% of people who transitioned to a CILA died and 19.6% returned to a SODC.
- People who originally transitioned to a CILA and remained in a CILA, either with the same provider or a different provider and either in the original residence or a different one, were middle-aged (41.5 years on average), had an average HRST score of 1.9 (lowest to low health risk), had an average ICAP Service Level score of 62.2 (Level 3 – regular personal care and/or close supervision), and had a mean IQ of 47.8.

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

- Of the 304 transitions from a SODC to a non-SODC setting, 62 returned to a SODC (21.4%). The largest percentage of returns (that were not missing a return reason) were for behavioral reasons (37.7%), followed by short-term therapy (24.6%), other (23.0%), and medical (14.8%).
- TA was provided to all 87.0% of returns for a behavioral reason (19 were provided behavioral TA and one was provided medical and behavioral TA). TA was provided to one return (out of nine, 11.1%) that returned for a medical reason (behavioral TA). Of those returning for another reason or for short-term therapy, only one (3.4%) received TA.
- Of the returns 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?

- Those transitioning to community settings (CILA and family settings), were generally younger (24-hour CILA: 40.5 mean age, I-CILA: 41.4 mean age, and family: 34.8 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 overall.
- 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?

- A total of 127 people died at a SODC (82) or after they transitioned out of a SODC (45). Of the 45 who died post-transition, 13 were missing their post-transition setting (28.9%) and 32 died in another setting (71.1%).
- People who died at a SODC had a mean age of 65.1 years, a mean HRST of 4.1 (high moderate to high health risk), and had been in the SODC for an average of 25.3 years. They also had an average ICAP Service Level score of 30.8, a score within Level 2 which represents the second most extensive support needs. 42.7% had at least one psychiatric disorder, and 11.0% 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 need 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, and had the highest ICAP Service Level score (less supports needed), lowest health risk, and highest IQ compared to both those who died in SODCs and other settings.

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

- 30 people (representing 35 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 59.3 years of age with an average LOS in a SODC of 18.7 years. Additionally, they had a mean HRST score of 4.4 out of 6 indicating a high moderate to high health risk. Their mean ICAP Service Level score was 26.7 which indicates the highest level of support needs and a mean IQ of 18.3.
- These individuals had significant health and personal support needs.

Themes

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

- Changing demographics and characteristics of the people transitioning:
  - Most people who transitioned were White (66.2%),
  - On average and for each individual fiscal year, most of those who transitioned were White, yet this percentage decreased from 76.6% in FY2018 to 60.0% in FY2020.
  - Those with family guardians decreased between FY2017 and FY2020, beginning with 60.3% and ending with 43.5%.

- The percentage of people who had a profound disability decreased each fiscal year, beginning with 39.7% in FY2017 and ending with 17.6% in FY2020. The portion of mild ID increased from 34.2% in FY2017 to 43.5% in FY2020.
- Mean HRST decreased each fiscal year and the percentage of people in the high risk HRST group (HRST ≥ 4) decreased by almost 15.4% across the four fiscal years.
- The frequency of return to a SODC from a non-SODC setting increased sharply from FY2017 through FY2019, but then went down again in FY2020.

❖ Increasing challenges in community settings with an increased number of people with ID and a psychiatric diagnosis:

- The majority of those who transitioned out of SODCs had a psychiatric diagnosis (61.8%). The percentage people transitioning with a psychiatric diagnosis increased from FY2017 to FY2020 (from 47.9% to 71.8%). The percentage of people who transitioned with a mood disorder increased by 13.6 percentage points from FY2017 and FY2020, and the frequency personality disorders also increased by 6.5 percentage points from FY2017 to FY2020.
- All of those that returned to a SODC from a CILA did so for behavioral reasons.

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 has faced for many years persist and continue to significantly impact services and supports for people with IDD in Illinois. 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 likely impact the community capacity of providers to support 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. 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.

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

Additional research should be completed to better understand the issues around transitions from SODCs. In particular, it is not possible to ascertain from the current data why some

transitions are successful and others are not. In-depth qualitative interviews with people who have transitioned could shed more light on this topic.

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

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

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

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., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M. L. (2020). *In-home & residential supports for persons with intellectual or developmental disabilities: Status and trends through 2017*. Retrieved from https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017

Lulinski, A., & Heller, T. (2021). Community Capacity to Provide Mental/Behavioral Health Services for People With IDD Transitioning From State-Operated Developmental Centers. *Intellectual and Developmental Disabilities, 59*(3), 224-238. doi:10.1352/1934-9556-59.3.224

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.