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

Transitions between January 1, 2013 – June 30, 2016

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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 January 1, 2013 to June 30, 2016. 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, 2011), from July 1, 2008 through June 30, 2009 (Lulinski Norris, Rizzolo, & Heller, 2012), and from July 1, 2009 through June 30, 2012 (Vasudevan, Rizzolo, Heller, & Lulinski, 2015) were conducted. This project is a continuation of those studies for the purpose of identifying trends related to depopulation of SODCs in Illinois. All data reported is as of March 2017.

Findings

How many individuals transitioned out of Illinois SODCs from January 1, 2013 through June 30, 2016?

- ➤ There were 431 live transitions out of SODCs in this timeframe. FY2016 only had 95 transitions, a 29% reduction from an average of 134.7 transitions in the three preceding years.
- > Only 29 of the transitions were short-term transitions for medical or behavioral care.
- ➤ The 431 transitions represent 411 people, 17 of whom transitioned twice, and one person who transitioned four times.
- > There were also 52 transitions because the person died within the SODC.

What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from January 1, 2013 through June 30, 2016?

- The average age of people who transitioned out of SODCs was 46.8 years of age, and the majority (70.6%) were male. Over half of people who transitioned had family members as their guardian (52.1%), while 30.2% had a public guardian. On average, people who transitioned had lived in the SODC for 14.7 years, ranging from less than a year to 78 years. Most people who transitioned were white (66.9%). The characteristics of people who transitioned varied slightly over the years, although there were no noteworthy differences. 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 (54.3%) of people who transitioned had a psychiatric diagnosis. During FY2013-14 the percentage was 61.2% and 63.1%, respectively, and the percent of people with a psychiatric diagnosis who transitioned out of a SODC decreased in FY2015 and FY2016 to 47.0% and 48.9%, respectively. The most frequent psychiatric diagnoses were mood disorders (22.6%) and psychotic disorders (11.2%). In addition to psychiatric diagnoses, 10.5% of people who transitioned were diagnosed with autism spectrum disorder (ASD) and 3.6% were diagnosed with Pervasive Developmental Disorder.

People who transitioned had varying levels of intellectual disability. Over one third had a profound intellectual disability (36.6%). People who transitioned had an average Inventory for Client and Agency Planning (ICAP) Service Level score of 28.7, putting them in service level 1 (out of 6), which indicates that a person needs "total personal care and intense supervision." They also had a mean Health Risk Screening Tool level of three ("moderate risk") and nearly one third (33.2%) 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 January 1, 2013 through June 30, 2016?

➤ Of the 431 transitions, almost half (49.9%) went to CILAs, 12.3% went to Skilled Nursing Facilities, 11.4% went to another setting, 8.8% went to an ICF/DD, 8.4% went to jail, 6.7% went to a family home, 2.3% went to another SODC, and one person went to a mental health center.

To what extent did individuals remain in their post-transition setting from January 1, 2013 through June 30, 2016?

- ➤ SODC staff follow-up with people who have transitioned for 12 months; since 40.4% of transitions occurred more than one year from data collection, their current status is unknown. 28.1% of transitions had a continuous placement, meaning that they were still in the setting that they transitioned to. 2.1% of transitions remained in the community with their same provider but in a different residence, and another 1.2% changed providers but remained in the community. 15.1% of people died after they transitioned, and 13.0% returned to a SODC.
- ➤ Of the 215 transitions that went to a CILA, nearly half remained in the same setting and with the same service provider (44.7%), while 3.3% remained with the same provider but in a different residence in the community and 1.9% remained in the community but with another provider. Only 2.8% of people who transitioned to a CILA died and 12.1% returned to a SODC. The rest (35.5%) were unknown because they transitioned more than 12 months prior to data collection, so data were not collected.
- ➤ 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 (45.2 years on average), had a HRST score of 2.20 (low to moderate health risk), had an IQ of 30.1, and had an ICAP Service Level score of 26.9 (Level 1 total personal care and intense supervision).

Why did people return to a SODC and did they receive TA from January 1, 2013 through June 30, 2016?

- ➤ Of the 421 transitions from a SODC to a non-SODC setting, 56 returned to a SODC (13.1%). The majority (57.1%) returned for behavioral reasons; 33.9% returned for "other" reasons; and 8.9% returned for medical reasons.
- ➤ Technical Assistance (TA) was provided to the majority of people who returned for a behavioral reason (26 of the 32 received TA, 19 received only behavioral TA and another seven received both behavioral and medical TA), but TA was not provided to the

- majority of people who returned to a SODC for a medical reason (only one of five received TA) or for another reason (only three of 18 received TA).
- ➤ Of the 26 people who returned to a SODC from a CILA, 24 did so because of a behavioral reason, one for a medical reason, and another for some other reason.

How do the demographics and characteristics of persons who transitioned compare across residential settings from January 1, 2013 through June 30, 2016?

- Those transitioning to community settings (CILA and family settings), were generally younger (CILA: 44.7 mean age, family: 32.1 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 5.02 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 January 1, 2013 through June 30, 2016?

- ➤ A total of 111 people died at a SODC (52) or after they transitioned out of a SODC (59 people).
- ➤ People who died at a SODC had a mean age of 58 years, a HRST of 4.4 (high moderate to high health risk), and had been in the SODC for an average of 25.5 years. They also had an ICAP Service Level score of 15.4 (Level 1 Total personal care and intense supervision). All had an ID, 71.2% had a psychiatric disorder, and 7.7% had ASD diagnosis.
- ➤ People who died post-transition generally died in other settings (66.1%). Only 10.2% of people who died post-transition died in a CILA, while 23.7% who died post-transition died in an ICF/DD or a SNF.
- ➤ The majority of the 111 deaths occurred at a SODC. Individuals who died in an "Other" setting were the oldest (mean age of 65.5 years) and those who died at SNFs had the highest health risk (mean HRST score of 5.30).

Themes

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

- Challenges in transitions and placements in FY2016.
 - The number of transitions out of SODCs decreased markedly (29%) in FY2016 compared to the previous three years.
 - Only 38.9% of transitions out of SODCs in FY2016 went to CILAs, again a markedly lower rate from their previous three years when about 53% of transitions went to CILAs.
 - FY2015 and FY2016 had much lower proportions of transitions for people with psychiatric diagnoses than the previous two years. During FY2013-14 the percentage was 61.2% and 63.1%, respectively, and the percent of people with a psychiatric diagnosis who transitioned out of a SODC decreased in FY2015 and FY2016 to 47.0% and 48.9%, respectively.

- ❖ Challenges in community settings for people with ID and a psychiatric diagnosis.
 - The majority of people who transitioned out of SODCs had a psychiatric diagnosis (54.3%). However, as noted in the previous bullet point, the rate of transition has slowed over the last two years.
 - The vast majority (24 of 26) of people who transitioned to a CILA and had to return to a SODC did so because of behavioral reasons.
 - While most of the 32 people who returned to an SODC for a behavioral reason received technical assistance, six people (18.8%) returned before they were able to receive technical assistance.

Introduction

The United States has a well-documented history of providing services to people with intellectual and/or developmental disabilities (IDD) in large publicly-funded congregate settings. The number of people with IDD in those settings peaked in 1967 (U.S. Department of Health, Education, and Welfare, 1972). Deinstitutionalization, moving people from State-Operated Developmental Centers (SODCs) into community settings has grown in popularity since, with the number of people living in SODCs declining by an average of 5% per year across the United States. 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, Hemp, Rizzolo, Tanis, Haffer, & Wu, 2015). As of May 2017, 14 states and the District of Columbia had no large state-run institutions.

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 FY2013 and FY2016, a timeframe when Illinois had seven active SODCs providing residential services to an average of 1746 people per month. Only two states, New Jersey and Texas, supported more people in state institutions than Illinois during this time (Braddock et al., 2015).

There is a large body of research that had found positive outcomes following transitions from institutional to community-based settings (Heller, Schindler & Rizzolo, 2008; Kozma, Mansell, & Beadle-Brown, 2009; Lakin, Larson, & Kim, 2011). 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, 2014).

The Institute on Disability and Human Development (IDHD) at the University of Illinois at Chicago has maintained a database of all transitions out of SODCs in Illinois since 2001. The last report in this series was completed in 2015 (Vasudevan, Rizzolo, Heller, & Lulinski, 2015), and in the spring of 2017, the Illinois Department of Human Services, Division of Developmental Disabilities (DHS-DDD) extended the database to include transitions from January 1, 2013 through June 30, 2016. The current report is very similar to previous reports in this series and asks the same primary questions (see the Methodology section), and aims to inform policymakers of the state and of the SODCs to improve transition planning in the future. All data in this report are from January 1, 2013 to June 30, 2016. January 1, 2013 – June 30, 2013 is referred to as FY2013 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 January 1, 2013 through June 30, 2016?

- 2) What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from January 1, 2013 through June 30, 2016?
- 3) To what type of residential setting did individuals transition from January 1, 2013 through June 30, 2016?
- 4) To what extent did individuals remain in their post-transition setting from January 1, 2013 through June 30, 2016?
- 5) Why did people return to a SODC and did they receive TA from January 1, 2013 through June 30, 2016?
- 6) How do the demographics and characteristics of persons who transitioned compare across residential settings from January 1, 2013 through June 30, 2016?
- 7) What are the demographics and characteristics of people who died since transitioning from a SODC from January 1, 2013 through June 30, 2016?

Methods

The current project investigated outcomes of individuals who moved out of Illinois' SODCs between January 1, 2013 and June 30, 2016, using the same methods as used in previous studies that covered the time period from October 1, 2001 through June 30, 2008 (Lulinski Norris, Rizzolo, & Heller, 2011), the time period of July 1, 2008 through June 30, 2009 (Lulinski Norris, Rizzolo, & Heller, 2012), and the time period of July 1, 2009 through June 30, 2012 (Vasudevan, Rizzolo, Heller, & Lulinski, 2015).

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 2017:

- 1) Gender
- 2) Date of birth
- 3) Race
- 4) Ethnicity
- 5) Date of admission to SODC
- 6) Whether the admission to a SODC was a short-term admission
- 7) SODC individual transitioned from
- 8) Date individual transitioned from SODC (discharge date)
- 9) Health Risk Screening Tool (HRST) level
- 10) ICAP Adaptive Behavior Scores
- 11) ICAP Service Level Score
- 12) ICAP Maladaptive Behavior Scores
- 13) IQ at time of transition
- 14) Presence and level of intellectual disability
- 15) Presence of autism spectrum disorder and diagnosis
- 16) Type of psychiatric diagnosis
- 17) Name of residential provider to which the individual transitioned and zip code
- 18) Type of post-transition residential 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 seven questions noted in the Introduction to this report.

Question 1. How many transitions occurred out of Illinois SODCs from January 1, 2013 through June 30, 2016?

Between January 1, 2013 and June 30, 2016 there were a total of 431 live transitions out of the Illinois State-Operated Developmental Center (SODC) system. These transitions represented 411 people, some of whom transitioned more than once into various settings. Of the 411 individuals who transitioned during the time period, 393 transitioned once (95.6%), 17 transitioned twice (4.1%), and one person transitioned four times (0.2%). Questions one through six focus on these 431 live transitions, while question seven focuses on transitions from SODCs where the person died in the SODC during this period (52 people) and on people who died in their transition setting following discharge (59 people) from a SODC.

As shown in Table 1 (next page), in terms of the number of transitions, FY2015 saw the most transitions from SODCs (135), closely followed by FY2014 (133). The data only includes half of FY2013, so doubling the state transitions during that half of the fiscal year would equal 136 transitions across that entire fiscal year, which closely matches the two fiscal years that follow. However, FY2016 only had 95 transitions, a 29% decrease in the number of transitions from the previous two fiscal years. The Governor Samuel H. Shapiro Developmental Center (Shapiro) accounted for the most transitions over this period (127, 29.5%). The second highest number of people who transitioned was from the Choate Developmental Center (Choate) with 107 (24.8%) transitions out of Choate. Together, Choate and Shapiro accounted for more than half of the transitions from SODCs in Illinois. Kiley Developmental Center (Kiley), Ludeman Developmental Center (Ludeman), and Murray Developmental Center (Murray) each transitioned about 13% of the total transitions from January 1, 2013 through June 30, 2016. Fox Developmental Center (Fox) and Mabley Developmental Center (Mabley) each transitioned less than 4% of the total transitions from January 1, 2013 through June 30, 2016. For the most part, the percentages of transitions by SODC matched its share of the population of people living in SODCs; however, Choate over performed as they counted for 24.8% of the transitions, but only had about 10% of the SODC population. On the other hand, Ludeman underperformed: they had 13.2% of the transitions, but almost 24% of the SODC population during the time period.

Table 1: SODC Transitions by Fiscal Year (January 1, 2013 – June 30, 2016)

SODC	FY2013	FY2014	FY2015	FY2016	Total	% of Total by SODC
Choate	11	33	42	21	107	24.8%
Fox	5	3	4	4	16	3.7%
Kiley	8	25	16	6	55	12.8%
Ludeman	8	14	17	18	57	13.2%
Mabley	3	7	2	1	13	3.0%
Murray	17	19	9	11	56	13.0%
Shapiro	16	32	45	34	127	29.5%
Total	68	133	135	95	431	
% of Total for FY	15.8%	30.9%	31.3%	22.0%		

Question 2. What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from January 1, 2013 through June 30, 2016?

Table 2 (next page) 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 January 1, 2013 through June 30, 2016. If an individual transitioned more than once in more than one fiscal year, they are included in each fiscal year. 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 411 individuals who transitioned out of the seven Illinois SODCs during the FY2013-2016 study period, the youngest was 18 years and the oldest was 94. The average age was 46.8 (SD = 16.3) years at the time of transition from January 1, 2013 through June 30, 2016. FY2013 had the highest average age of 48.3 years (SD = 12.7), while FY2014 was the lowest at 44.9 years of age (SD = 16.5).

Length of Stay (LOS)

People who transitioned out of a SODC from January 1, 2013 through June 30, 2016 had lived in the SODC for an average of 14.7 years, ranging from less than a year to 78 years (SD=15.4).

Gender

Across the four years, most of the individuals who transitioned out of the SODCs were male (70.6%). This percentage ranged from a low of 66.0% in FY2013 to a high of 73.8% in FY2016.

Race

Most people who transitioned out of SODCs were white (66.9%). In FY2013, 77.6% of transitions were white.

Guardianship Status

Approximately half of the individuals who transitioned out of SODCs from January 1, 2013 through June 30, 2016 had family members as their guardians (52.1%). The percentage of transitions with a family member as a guardian ranged from 43.8% in FY2014 to 55.3% in FY2016. About a third of the 411 individuals that transitioned had a public guardian (124, 30.2%).

Table 2: Demographics by Fiscal Year (January 1, 2013 – June 30, 2016)

Table 2. Defilographics by Fiscal Teal (January 1, 2013 – Julie 30, 2010)										
	FY20 (n =		FY20 (n = 1			2015 132)		.016 94)	FY	2013- 2016 : 411)
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Age (years)	48.3	12.7	44.9	16.5	47.3	16.5	48.1	17.6	46.8	16.3
Length of Stay (years)	17.4	16.6	13.3	15.2	13.1	13.9	16.4	16.4	14.7	15.4
	n	%	n	%	n	%	n	%	n	%
Gender										
Male	47	70.1	96	73.8	93	70.5	62	66.0	290	70.6
Female	20	29.9	34	26.2	39	29.5	32	34	121	29.4
Race										
White	52	77.6	84	64.6	80	60.6	68	72.3	275	66.9
Non-White	15	22.4	46	35.4	52	39.4	26	27.7	136	33.1
Guardian St	atus									
Legally competent	7	10.4	27	20.8	21	15.9	14	14.9	67	16.3
Public guardian	21	31.3	44	33.8	40	30.3	26	27.7	124	30.2
Family Guardian	37	55.2	57	43.8	70	53.0	52	55.3	214	52.1
Non- Family Guardian	2	3.0	1	0.8	1	0.8	1	1.1	5	1.2
Other/ unknown	0	0.0	1	0.8	0	0.0	1	1.1	1	0.2

Psychiatric Diagnosis

Of the 411 individuals who transitioned during FY2013 through FY2016, 223 people (54.3%) had a psychiatric diagnosis. Figure 1 (next page) illustrates the percentages of those transitioning from January 1, 2013 through June 30, 2016 with a diagnosed psychiatric disorder.

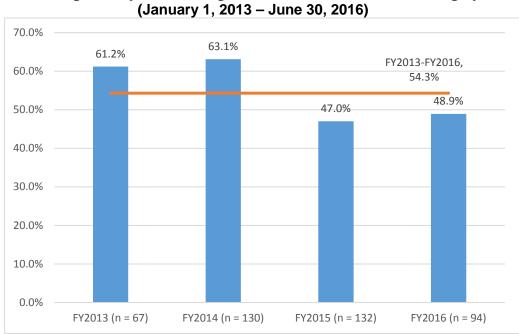


Figure 1: Percentage of Psychiatric Diagnosis of Individuals Transitioning by Fiscal Year (January 1, 2013 – June 30, 2016)

Table 3 (next page) describes the percentage of individuals diagnosed with a psychiatric disorder by fiscal year. Between January 1, 2013 and June 30, 2016, the majority had a psychiatric diagnosis (54.3%); nearly a third had one psychiatric diagnosis (33.8%) and 11.7% had more than one psychiatric diagnosis. Between January 1, 2013 through June 30, 2016 (n = 411), the most common psychiatric diagnoses were mood disorder (22.6%), psychotic disorder (11.2%), impulse control disorder (5.8%), childhood disorders (4.4%), anxiety disorders (3.9%), and personality disorders (2.7%).

Table 3: Psychiatric Diagnosis by Fiscal Year (January 1, 2013 – June 30, 2016)

14515 61	FY20		FY20		FY20	(January	FY20		FY20	
	(n = 6)		(n =		(n =		(n = 9)		FY20	
			`	,	`	,		•	(n = 4)	
	n	%	n	%	n	%	n	%	n	%
Number of psychiatric										
diagnoses										
0	41	61.2%	82	63.1%	63	47.7%	46	48.9%	224	54.5%
1	14	20.9%	35	26.9%	53	40.2%	38	40.4%	139	33.8%
2	7	10.4%	10	7.7%	10	7.6%	8	8.5%	35	8.5%
3+	5	7.5%	3	2.3%	6	4.5%	2	2.2%	13	3.2%
Psychiatric diagnosis*										
Mood	11	16.4%	26	20.0%	33	25.0%	26	27.7%	93	22.6%
Psychotic	5	7.5%	11	8.5%	21	15.9%	12	12.8%	46	11.2%
Impulse	4	6.0%	6	4.6%	6	4.5%	8	8.5%	24	5.8%
Childhood	2	3.0%	6	4.6%	6	4.5%	5	5.3%	18	4.4%
Anxiety	10	14.9%	2	1.5%	3	2.3%	2	2.1%	16	3.9%
Personality	3	4.5%	3	2.3%	5	3.8%	2	2.1%	11	2.7%
Substance	0	0.0%	4	3.1%	4	3.0%	2	2.1%	10	2.4%
Unspecified, non- psychotic	2	3.0%	3	2.3%	4	3.0%	1	1.1%	10	2.4%
Sexual or Gender Identity Disorder	1	1.5%	1	0.8%	5	3.8%	1	1.1%	7	1.7%
Adjustment	1	1.5%	2	1.5%	2	1.5%	1	1.1%	5	1.2%
Delirium or Dementia	1	1.5%	0	0.0%	1	0.8%	1	1.1%	3	0.7%
Somatoform	1	1.5%	0	0.0%	0	0.0%	0	0.0%	1	0.2%
*Not mutually ex	xclusiv	е								

Level of Intellectual Disability

Of the 411 individuals who transitioned out of a SODC between January 1, 2013 and June 30, 2016, nearly all had a diagnosis of intellectual disability (ID; 97.3%). Figure 2 (next page) illustrates the level of ID by fiscal year. Over one third (36.6%) of those who transitioned during the four years had a profound intellectual disability, ranging from 29.7% in FY2014 to 50.7% in FY2013. Mild was the next highest category, ranging from 17.9% in FY2013 to 29.7% in FY2014.

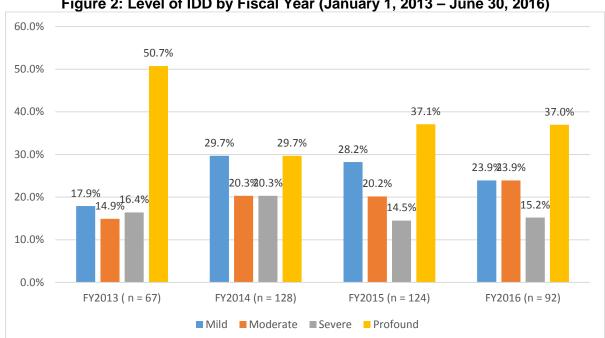


Figure 2: Level of IDD by Fiscal Year (January 1, 2013 – June 30, 2016)

Autism Spectrum Disorder (ASD) Diagnosis

During the four years, over one in ten (10.5%) of people who transitioned had a diagnosis of Autism Spectrum Disorder (ASD) while 3.6% 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 (January 1, 2013 – June 30, 2016)

		2013 = 67)		2014 130)		2015 132)		2016 = 94)	FY2	013- 2016 411)
	#	%	#	%	#	%	#	%	#	%
No ASD Diagnosis	63	94.0	103	79.2	114	86.4	85	90.4	353	85.9
Autism	4	6.0	17	13.1	16	12.1	6	6.4	43	10.5
PDD	0	0.0	10	7.7	2	1.5	3	3.2	15	3.6

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 (next page).

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 January 1, 2013 and June 30, 2016 was 1 - 87. The average ICAP Service Level Score for individuals who transitioned between January 1, 2013 and June 30, 2016 was 28.7 (sd = 24.8), which indicates a need for total personal care and intense supervision. Table 6 describes the average, minimum, and maximum ICAP Service Level Scores between January 1, 2013 and June 30, 2016 by fiscal year.

Table 6: ICAP Service Level Scores by Fiscal Year (January 1, 2013 – June 30, 2016)

	FY2013 (n=51)	FY2014 (n=116)	FY2015 (n=123)	FY2016 (n=84)	FY2013 – FY2016 (n = 367)
Minimum	1	1	1	1	1
Mean	28.0	31.6	27.8	26.4	28.7
Maximum	86	82	84	87	87

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 January 1, 2013 through June 30, 2016 range from level 1 to level 6 and the average HRST score was 3.00 (sd = 1.8), which is in the moderate risk level. Table 8 (next page) shows the percentage of people with high HRST scores (≥ 4) and the mean HRST score for each fiscal year. FY2013 had the highest percentage of people in the high HRST score group with a mean HRST of 3.56 (moderate to high moderate

risk level). FY2014 had the lowest percentage of people in the high HRST score group with a mean HRST of 2.66 (low to moderate risk level).

Table 8: HRST Health Risk Levels (January 1, 2013 – June 30, 2016)

	FY2013 (n=66)	FY2014 (n=122)	FY2015 (n=125)	FY2016 (n=89)	FY2013 - FY2016 (n = 391)
% High HRST (> 4)	29 (43.9%)	28 (23.0%)	43 (34.4%)	37 (41.6%)	130 (33.2%)
Mean HRST	3.56	2.66	2.87	3.39	3.00

Question 3. To what type of residential setting did individuals transition from January 1, 2013 through June 30, 2016?

Table 9 describes the percentage of transitions from each SODC to various types of residential settings between January 1, 2013 and June 30, 2016. Though post-transition settings varied by SODC, transitions out of a SODC and into a CILA setting made up nearly half (49.9%) of the 431 transitions during that period. The second most common post-transition setting was a Skilled Nursing Facility (SNF), which made up 12.3% of the transitions during that period. Approximately 8.8% of transitions moved into an Intermediate Care Facility for Developmental Disabilities (ICF/DD) and 8.4% went to jail. A small number of transitions went to another SODC (2.3%) or to a State-Operated Mental Health Center (MHC; 0.2%). 6.7% of individuals moved in with a family member. The remaining 11.4% transitioned to other settings.

Ludeman had the highest percent of transitions that went to CILAs (70.2%) while, Fox had the lowest percent at 18.8%. The majority of transitions from Fox went to SNFs (62.5%). These differences are expected as individuals who live at Fox are typically the most medically fragile.

Table 9: Discharge Setting by SODC Discharged From (January 1, 2013 – June 30, 2016)

				2010)				
	Choate (n = 107)	Fox (n = 16)	Kiley (n = 55)	Ludem an (n = 57)	Mabley (n = 13)	Murray (n = 56)	Shapiro (n = 127)	Total (n = 431)
CILA	33.6%	18.8%	69.1%	70.2%	46.2%	53.6%	48.8%	49.9%
ICF/DD	5.6%	18.8%	0.0%	12.3%	30.8%	10.7%	9.4%	8.8%
Other SODC	0.0%	0.0%	3.6%	3.5%	7.7%	8.9%	0.0%	2.3%
Family	14.0%	0.0%	0.0%	8.8%	15.4%	3.6%	3.9%	6.7%
SNF	2.8%	62.5%	10.9%	3.5%	0.0%	23.2%	15.0%	12.3%
Jail	33.6%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	8.4%
MHC	0.0%	0.0%	1.8%	0.0%	0.0%	0.0%	0.0%	0.2%
Other	10.3%	0.0%	14.5%	1.8%	0.0%	0.0%	22.8%	11.4%

Table 10 (next page) illustrates the transition settings by fiscal year. The lowest percentage of transitions to a CILA happened in FY2016 (38.9%) while the highest percentage of transitions to SNFs (16.8%) also happened in that year.

Table 10: Discharge Settings by Fiscal Year (January 1, 2013 – June 30, 2016)

	FY2013 (n = 68)	FY2014 (n = 133)	FY2015 (n = 135)	FY2016 (n = 95)	Total (n = 431)
CILA	45.6%	51.9%	57.8%	38.9%	49.9%
ICF/DD	20.6%	7.5%	5.9%	6.3%	8.8%
Other SODC	0.0%	5.3%	0.0%	3.2%	2.3%
Family	5.9%	7.5%	6.7%	6.3%	6.7%
SNF	14.7%	9.0%	11.1%	16.8%	12.3%
Jail	5.9%	6.8%	8.1%	12.6%	8.4%
MHC	0.0%	0.8%	0.0%	0.0%	0.2%
Other	7.4%	11.3%	10.4%	15.8%	11.4%

Question 4. To what extent did individuals remain in their post-transition setting from January 1, 2013 through June 30, 2016?

Regulations only require the Department of Human Services follow individuals for one year after they transitioned. Because data for this report that covers the second half of FY2013 through FY2016 was collected in March 2017, the SODCs from which individuals transitioned were not required to track the current living situation of many of these individuals. As a result, the current status of 40.4% of the transitions during this period are unknown. Of those for whom data was available, 28.1% had maintained a continuous placement in their new setting following that transition.

Table 11: Current Status of Transitioned Individuals by Fiscal Year (January 1, 2013 – June 30, 2016)

	FY2013 (n = 68)	FY2014 (n = 133)	FY2015 (n = 135)	FY2016 (n = 95)	FY2013- FY2016 (n = 431)
Continuous placement	20.6%	34.6%	28.9%	23.2%	28.1%
Different residence, same provider	1.5%	3.0%	3.0%	0.0%	2.1%
Changed provider	0.0%	2.3%	1.5%	0.0%	1.2%
Returned to SODC	13.2%	9.0%	17.0%	12.6%	13.0%
Deceased	14.7%	12.8%	11.9%	23.2%	15.1%
Unknown	50.0%	37.6%	37.8%	41.1%	40.4%
Missing	0.0%	0.8%	0.0%	0.0%	0.2%

Of the 215 transitions from a SODC to a CILA from January 1, 2013 through June 30, 2016 (Figure 3 on next page), nearly half (44.7%) remained at the same home and with the same service provider (as of June 30, 2016), and 3.3% of the transitions remained with the same provider but changed homes. Four remained in the community but changed providers (1.9%);

26 returned to a SODC (12.1%), six died (2.8%), and the current status of 35.3% remained "unknown" because the SODCs were not required to follow them beyond the one year.

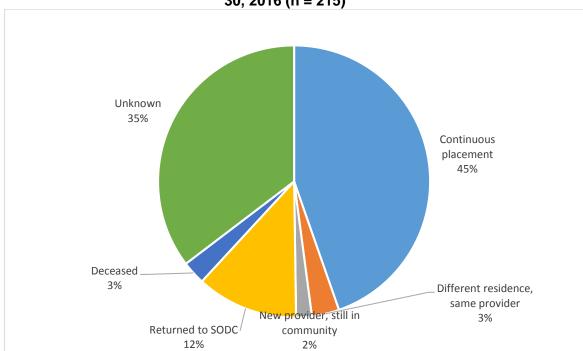


Figure 3: Current Status of Transitions from a SODC to a CILA: January 1, 2013 – June 30, 2016 (n = 215)

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 45.2 years, mean HRST score of 2.20, mean ICAP Service Level score of 30.1, and mean IQ of 26.9 (Table 12).

Table 12: Characteristics of Transitions to and Remained in the Community by Fiscal Year (January 1, 2013 – June 30, 2016)

	Tour (ourise	, .,		<u>'</u>	
	FY2013 (n = 13)	FY2014 (n = 44)	FY2015 (n = 37)	FY2016 (n = 13)	FY2013- FY2016 (n = 107)
Age (years)	46.9	44.1	46.0	44.6	45.2
HRST	2.77	2.18	2.06	2.08	2.20
IQ	20.7	27.4	30.4	34.5	30.1
ICAP Service Level	23.0	31.5	23.4	25.2	26.9

Question 5. Why did people return to a SODC and did they receive TA from January 1, 2013 through June 30, 2016?

Between January 1, 2013 and June 30, 2016, of the 421 transitions from a SODC to a non-SODC setting, 56 returned to a SODC (13.1%). In FY2013, 13.2% returned to a SODC, 9.5% in FY2014, 17.0% in FY2015, 13.0% in FY2016 (Figure 4).

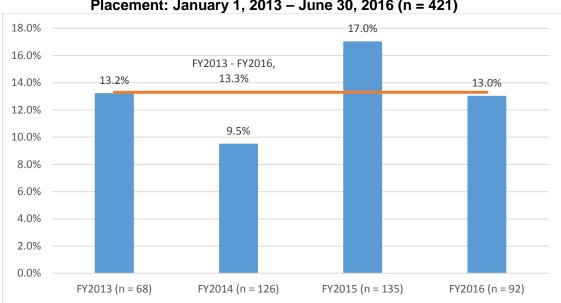


Figure 4: Frequency of Return to a SODC from a Non-SODC Post-Transition Placement: January 1, 2013 – June 30, 2016 (n = 421)

The discharge summary sheet had the following response options for reason for return to a SODC: medical, behavioral, or "other." Figure 5 illustrates the reasons individuals returned to a SODC after discharge. Of the 56 returns to a SODC, the majority (57.1%) returned for behavioral reasons; 33.9% returned for "other" reasons; and 8.9% returned for medical reasons.

Table 13 shows the number of transitions that returned to an SODC, along with the percent of those returns receiving technical assistance. The majority of returns were to Choate, who also had the lowest rate (21.1%) of providing TA to returners.

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

SODC	Number of Returns	Number Receiving TA	Percent Receiving TA
Choate	19	4	21.1%
Fox	5	1	20.0%
Kiley	6	3	50.0%
Ludeman	6	4	66.7%
Mabley	2	2	100.0%
Murray	9	9	100.0%
Shapiro	9	7	77.8%

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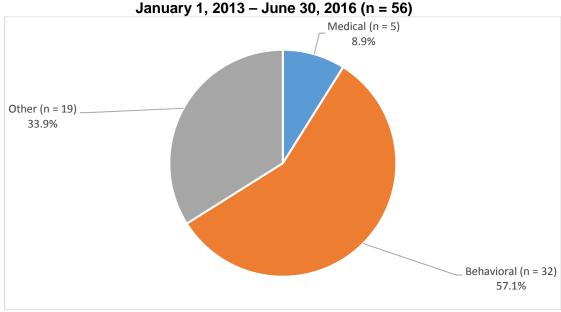


Figure 5: Reasons for Return to a SOD77C from a Non-SODC Post-Transition Setting:

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, or dietary issues but did not specify how the support was delivered.

Figure 6 (next page) compares the reason (medical, behavioral, or other (which includes dietary and DLA [routine follow-up]), for an individual's return to a SODC by whether or not they received medical or behavioral TA. Data is presented from January 1, 2013 through June 30, 2016. Of the five individuals who returned to a SODC because of medical reasons, most did not receive any TA (80.0%); only one person who returned because of medical reasons received medical and behavioral TA (20.0%). Conversely, for those who returned to a SODC because of behavioral reasons, less than one fifth did not receive any TA (6, 18.8%); 19 (59.4%) received behavioral TA, and 7 (21.9%) received medical and behavioral TA. More than three quarters of people who returned for another reason did not receive TA (15, 83.3%), while three (16.7%) received medical and behavioral TA.

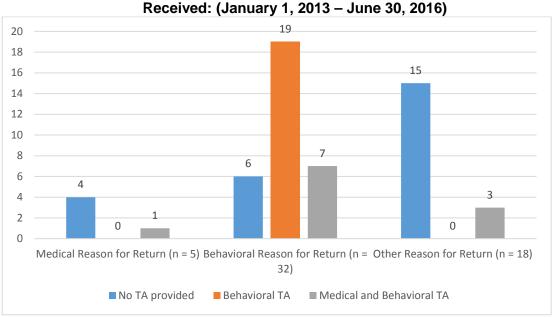


Figure 6: Reason for Return to SODC from a Non-SODC Post-Transition Setting by TA

Table 14 compares the reason (medical, behavioral, other (which includes dietary and DLA [routine follow-up]), for an individual's return to a SODC by the setting from which they returned to the SODC. The vast majority (92.3%) of people who returned to a SODC did so for a behavioral reason. People who returned to a SODC from a SNF did so for medical and behavioral reasons (26.6% each) and 46.7% returned for another reason.

Table 14: Reason for Return to a SODC by Non-SODC Post-Transition Placement: (January 1, 2013 – June 30, 2016)

	CILA (n=26)	ICF/DD (n=1)	Family (n=5)	SNF (n=15)	Jail (n=5)	Other (n=3)
Medical	1 (3.8%)	0	0	4 (26.6%)	0	0
Behavioral	24 (92.3%)	1 (100%)	2 (40%)	4 (26.6%)	0	1 (33.3%)
Other	1 (3.8%)	0	3 (60%)	7 (46.7%)	5 (100%)	2 (66.7%)

Question 6. How do demographics and characteristics of persons who transitioned compare across residential settings from January 1, 2013 through June 30, 2016?

Those who transitioned to community settings, including CILAs and family settings, were generally younger (44.7 mean age for CILAs and 32.1 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,

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 institutional settings including ICF/DDs and SNFs.

Table 15: Comparing Characteristics of Transitions by Post-Transition Residential Setting (January 1, 2013 – June 30, 2016)

	Setting (Sandary 1, 2013 – Suite 30, 2010)							
	CILA (n = 215)	ICF/DD (n = 38)	SODC (n = 10)	Family (n = 29)	SNF (n = 53)	Jail (n = 36)	MHC (n = 1)	Other (n = 49)
	mean	mean	mean	mean	mean	mean	mean	mean
Age (years)	44.7	55.2	36.9	32.1	58.8	30.4	31.0	61.6
LOS @ previous SODC (years)	12.1	23.1	10.9	6.8	25.8	0.7	0.1	24.8
HRST	2.70	3.41	2.80	1.80	5.02	1.00	3.00	4.00
ICAP Service Level	33.9	23.4	37.5	18.2	27.8	7.97	67.00	29.8
IQ	31.5	20.9	35.4	33.3	19.7	26.9	37.0	24.0
	%	%	%	%	%	%	%	%
Frequency of ID	99.5%	100.0%	100.0%	96.6%	100.0%	75.0%	100.0%	100.0%
Frequency of Psychiatric	53.5%	55.3%	70.0%	48.3%	77.4%	30.6%	100.0%	49.0%
Frequency of ASD	19.1%	10.5%	10.0%	17.2%	5.7%	0.0%	0.0%	10.2%

Question 7. What are the demographics and characteristics of people who died from January 1, 2013 through June 30, 2016?

A total of 111 people died either at a SODC or after they had transitioned out of a SODC from January 1, 2013 through June 30, 2016. 52 people died in a SODC and 59 people died in the community.

Between January 1, 2013 and June 30, 2016, 10.8% of the total transitions (52 out of 483) died while at a SODC. Table 16 (next page) describes the characteristics of the 52 individuals who died while at a SODC between January 1, 2013 and June 30, 2016. On average, the mean age for individuals who died in a SODC was 58 years and had a mean HRST score of 4.4 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 15.4) and a mean IQ of 17.7. This means that the people who died in a SODC had poor health overall. All 52 individuals had an ID, while 71.2% had at least one psychiatric diagnosis, and 7.7% were also diagnosed with Autism Spectrum Disorder.

Table 16: Characteristics of Individuals who Died at SODC: January 1, 2013 – June 30, 2016 (n = 52)

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	Mean	SD			
Age (years)	58	12.0			
HRST	4.4	1.5			
Length of Stay (years)	25.5	14.7			
IQ	17.7	15.6			
ICAP Service Level	15.4	16.3			
	n	%			
Frequency of ID	52	100.0%			
Frequency of Psychiatric Disorder	37	71.2%			
Frequency of ASD	4	7.7%			

A total of 59 individuals died after transitioning out of a SODC in Illinois between January 1, 2013 and June 30, 2016. Figure 7 illustrates where individuals were living at the time of their death over the course of the current study period. About two-thirds of the deaths post-transition occurred at "other" settings (66.1%); 16.9% of deaths occurred at other SNFs; 10.2% of deaths occurred at CILAs; and 6.8% occurred at an ICF/DD.

Figure 7: Deaths by Type of Post-Transition Residential Setting: January 1, 2013 – June 30, 2016 (n = 59)

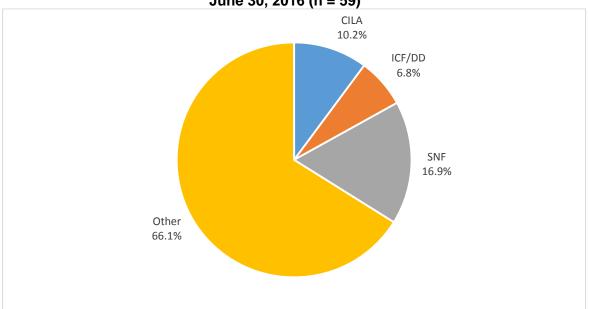


Table 17 (next page) compares demographic characteristics of individuals who died (n = 111) across settings. The majority of the 111 deaths occurred at a SODC (46.8%), followed by "Other" setting (35.1%), SNF (9.0%), CILA (5.4%), and ICF/DD (3.6%). Individuals that died in an "Other" setting were the oldest (mean age = 65.5 years) and those who died at SNFs had the highest health risk (mean HRST score = 5.30). Individuals that died at a SODC had a mean age of 58.0 years and a mean HRST score of 4.37. Individuals that died at a CILA had a mean age of 57.8 years and a mean HRST score of 3.00.

Table 17: Comparing Characteristics of Individuals who Died across Settings: January 1, 2013 – June 30, 2016 (n = 111)

	SODC (n = 52)	SNF (n = 10)	CILA (n = 6)	ICF/DD (n = 4)	Other (n = 39)
	Mean	Mean	Mean	Mean	Mean
Age (years)	58.0	62.5	57.8	65.2	65.5
LOS @ previous SODC (years)	24.5	28.0	8.9	2.7	29.1
HRST	4.37	5.30	3.00	4.25	4.56
ICAP Service Level	15.4	25.0	28.8	49.0	35.0
IQ	17.7	19.1	30.0	49.5	22.6

Conclusion

This study sought to answer seven 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 January 1, 2013 through June 30, 2016?

- ➤ There were 431 live transitions out of SODCs in this timeframe. FY2016 only had 95 transitions, a 29% reduction from an average of 134.7 transitions in the three preceding vears.
- > Only 29 of the transitions were short-term transitions for medical or behavioral care.
- ➤ The 431 transitions represent 411 people, 17 of whom transitioned twice, and one person who transitioned four times.
- ➤ There were also 52 transitions because the person died within the SODC.

What are the demographics and characteristics of those who transitioned out of SODCs in Illinois from January 1, 2013 through June 30, 2016?

- The average age of people who transitioned out of SODCs was 46.8 years of age, and the majority (70.6%) were male. Over half of people who transitioned had family members as their guardian (52.1%), while 30.2% had a public guardian. On average, people who transitioned had lived in the SODC for 14.7 years, ranging from less than a year to 78 years. Most people who transitioned were white (66.9%). The characteristics of people who transitioned varied slightly over the years, although there were no noteworthy differences. It is not possible for the evaluation team to assess whether these demographic characteristics differed from the population of people living in SODCs.
- ➤ Over half (54.3%) of people who transitioned had a psychiatric diagnosis. During FY2013-14 the percentage was 61.2% and 63.1%, respectively, and the percent of people with a psychiatric diagnosis who transitioned out of a SODC decreased in FY2015 and FY2016 to 47.0% and 48.9%, respectively. The most frequent psychiatric diagnoses were mood disorders (22.6%) and psychotic disorders (11.2%). In addition to psychiatric diagnoses, 10.5% of people who transitioned were diagnosed with Autism Spectrum Disorder and 3.6% were diagnosed with Pervasive Developmental Disorder.
- People who transitioned had varying levels of intellectual disability. Over one third had a profound intellectual disability (36.6%). People who transitioned had an average Inventory for Client and Agency Planning (ICAP) Service Level score of 28.7, putting them in service level 1 (out of 6), which indicates that a person needs "total personal care and intense supervision." They also had a mean Health Risk Screening Tool level of three ("moderate risk") and nearly one third (33.2%) 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 January 1, 2013 through June 30, 2016?

➤ Of the 431 transitions, almost half (49.9%) went to CILAs, 12.3% went to Skilled Nursing Facilities, 11.4% went to another setting, 8.8% went to an ICF/DD, 8.4% went to jail, 6.7% went to a family home, 2.3% went to another SODC, and one person went to a mental health center.

To what extent did individuals remain in their post-transition setting from January 1, 2013 through June 30, 2016?

- ➤ SODC staff follow-up with people who have transitioned for 12 months; since 40.4% of transitions occurred more than one year from data collection, their current status is unknown. 28.1% of transitions had a continuous placement, meaning that they were still in the setting that they transitioned to. 2.1% of transitions remained in the community with their same provider but in a different residence, and another 1.2% changed providers but remained in the community. 15.1% of people died after they transitioned, and 13.0% returned to a SODC.
- ➤ Of the 215 transitions that went to a CILA, nearly half remained in the same setting and with the same service provider (44.7%), while 3.3% remained with the same provider but in a different residence in the community and 1.9% remained in the community but with another provider. Only 2.8% of people who transitioned to a CILA died and 12.1% returned to a SODC. The rest (35.5%) were unknown because they transitioned more than 12 months prior to data collection, so data were not collected.
- ➤ 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 (45.2 years on average), had a HRST score of 2.20 (low to moderate health risk), had an IQ of 30.1, and had an ICAP Service Level score of 26.9 (Level 1 total personal care and intense supervision).

Why did people return to a SODC and did they receive TA from January 1, 2013 through June 30, 2016?

- Of the 421 transitions from a SODC to a non-SODC setting, 56 returned to a SODC (13.1%). The majority (57.1%) returned for behavioral reasons; 33.9% returned for "other" reasons; and 8.9% returned for medical reasons.
- ➤ Technical Assistance (TA) was provided to the majority of people who returned for a behavioral reason (26 of the 32 received TA, 19 received only behavioral TA and another seven received both behavioral and medical TA), but TA was not provided to the majority of people who returned to a SODC for a medical reason (only one of five received TA) or for another reason (only three of 18 received TA).
- ➤ Of the 26 people who returned to a SODC from a CILA, 24 did so because of a behavioral reason, one for a medical reason, and another for some other reason.

How do the demographics and characteristics of persons who transitioned compare across residential settings from January 1, 2013 through June 30, 2016?

Those transitioning to community settings (CILA and family settings), were generally younger (CILA: 44.7 mean age, family: 32.1 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 5.02 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 January 1, 2013 through June 30, 2016?

- ➤ A total of 111 people died at a SODC (52) or after they transitioned out of a SODC (59 people).
- ➤ People who died at a SODC had a mean age of 58 years, a HRST of 4.4 (high moderate to high health risk), and had been in the SODC for an average of 25.5 years. They also had an ICAP Service Level score of 15.4 (Level 1 Total personal care and intense supervision). All had an ID, 71.2% had a psychiatric disorder, and 7.7% had ASD diagnosis.
- ➤ People who died post-transition generally died in other settings (66.1%). Only 10.2% of people who died post-transition died in a CILA, while 23.7% who died post-transition died in an ICF/DD or a SNF.
- ➤ The majority of the 111 deaths occurred at a SODC. Individuals who died in an "Other" setting were the oldest (mean age of 65.5 years) and those who died at SNFs had the highest health risk (mean HRST score of 5.30).

Themes

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

- Challenges in transitions and placements in FY2016.
 - The number of transitions out of SODCs decreased markedly (29%) in FY2016 compared to the previous three years.
 - Only 38.9% of transitions out of SODCs in FY2016 went to CILAs, again a markedly lower rate from their previous three years when about 53% of transitions went to CILAs.
 - FY2015 and FY2016 had much lower proportions of transitions for people with psychiatric diagnoses than the previous two years. During FY2013-14 the percentage was 61.2% and 63.1%, respectively, and the percent of people with a psychiatric diagnosis who transitioned out of a SODC decreased in FY2015 and FY2016 to 47.0% and 48.9%, respectively.
- Challenges in community settings for people with ID and a psychiatric diagnosis.
 - The majority of people who transitioned out of SODCs had a psychiatric diagnosis (54.3%). However, as noted in the previous bullet point, the rate of transition has slowed over the last two years.
 - The vast majority (24 of 26) of people who transitioned to a CILA and had to return to a SODC did so because of behavioral reasons.
 - While most of the 32 people who returned to an SODC for a behavioral reason received technical assistance, six people (18.8%) 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 lack of a comprehensive state budget to fund services for people with ID may play a large role, especially as suggested by the challenges in FY2016 when the implications of the lack of a comprehensive state budget became more clear. Without a budget that will reimburse them for services, providers have faced challenges with regard to maintaining a workforce necessary for additional CILAs and other community settings to operate.

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.

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

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

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