

Court Monitor's Response to Defendants' Motion to Vacate the Consent Decree

It seems overly simple to say that adults with intellectual and developmental disabilities (I/DD) are in danger of losing their rights and therefore need protection from harm in order to live as others do. It is much more complex, particularly when these individuals are living in a state where people with I/DD are not adequately served at this time.

A Ligas Family Town Hall was most recently held on April 17, 2024. It was created to bring together Ligas Class Members, their families, stakeholders, and others to share stories and hear updates from the Illinois Department of Human Services, Division of Developmental Disabilities (DDD), the Court Monitor, Plaintiffs Counsel, the Arc of Illinois' Ligas Family Advocates, and other interested individuals. Foremost of concern for participants at this most recent meeting was the possibility of termination of the Ligas Consent Decree. People spoke eloquently and passionately about their concerns, frustrations, and fears. One self-advocate declared, ***"I thought Illinois wanted to go forward, not millions of steps backward. It's not about things on paper. It's about people's lives and I think that Illinois needs to wake up and start believing in people with disabilities and serving us in the right way."***

Other speakers stated:

- *"It is chilling to think what would happen without the Consent Decree's protections; Illinois residents with I/DD are not adequately served at this time."*
- *"There are very high caseloads for Independent Service Coordinators, along with additional responsibilities."*
- *"High needs individuals are being ignored throughout the state."*
- *"There are no CILA placements for those with medium to high medical or behavioral support needs."*
- *"We have to place folks on waitlists for many, many months due to staffing shortages."*
- *"The State is saying that they have complied with the Decree's terms but we disagree with that."*
- *"I think there are a lot more investments in community living that need to be made before the State is in compliance."*
- *"Every class member is entitled to community-based services, regardless of having average needs, low needs, high needs, medical needs and regardless of whether they are in crisis or not."*

The Motion to Terminate does not make sense at this time and juncture. Others who learned about the possible termination of the Consent Decree have communicated with the Court Monitor through phone calls or by sending emails and affidavits. Following are excerpts of their concerns and positions:

1. *"As parents of an adult daughter with Down syndrome, we want to strongly state our opinion on the State of Illinois filing a motion in Federal Court to dismiss the Ligas Consent Decree. We have tried to plan for our daughter but really haven't found anything that would even be acceptable. We need more decent CILAs and good providers. We need to get more people out of the institutions and into home*

environments."

2. *"Illinois does not have a robust community system needed to support the right to live or remain in the community and allow meaningful choice between institution or community support. Regarding community housing, most CILAs in our area have increased their capacity to eight individuals. This large household size precludes individuals with high needs. Of all of the CILAs in our area who received packets, only one showed an interest in our son, and after meeting with the agency and exchanging phone calls, the agency chose another individual for the spot. We feel the Illinois system has failed our son. We live in an area with limited resources and agencies can easily fill slots with higher functioning individuals. Our son's long-term outcomes are not promising, and as we age, we worry about his future when we can no longer care for him."*
3. *"My 24-year-old who was born with Down syndrome has spent his life building his community, honing life skills, and making connections in his hometown where he chooses to live. He and his family want a meaningful housing choice once he is ready to live outside our family as independently as possible with the appropriate supports to maximize the independence he has worked so hard to achieve. We are concerned that he will not reach his supportive living goals due to shortages of service providers, limited capacity of service agencies, overly complex and confusing funding and benefit mechanisms, and waiver choices that don't meet his goals. Illinois must improve community living outcomes for all of these issues. Our people with I/DD and their families depend on this."*
4. *"Illinois does not have a robust community system needed to support the right to live or remain in the community and allow meaningful choice between institutionalization or community supports. Our son has moderate cognitive disabilities and significant delays owing to having both Down syndrome and autism. He is*

nonverbal and needs assistance with many activities of daily living. We are fortunate in that our son automatically had adult funding by virtue of having been in a residential school, which made him a Ligas class member. When he aged out, finding an appropriate home took a long time. Everyone was grateful when a new home opened which was spacious, beautiful, and had great staff. He had a community-based day program based on his interests and his home life was also based on his interests. However, CILA life in Illinois has its ups and downs due to lack of services and choices and lack of decent workers. Staff left without notice twice during the first four months. That house, which opened in September, had staffing and financial issues and determined they could no longer afford to operate it. Again, we were lucky, and a friend put us in touch with an agency opening homes and they accepted our son. The Ligas Consent Decree has made modest gains in how Illinois funds and operates I/DD community living but is nowhere close to attaining the changes needed for the Decree to end.”

5. *“The ISCs are so overburdened with workload and paperwork that they are not able to keep up. When we’ve had our yearly ISC review over the past few years, we never had any follow-up questions or concerns that the ISC was going to look into and get back to us with answers. Our ISC came out on 4/5/24 of this year for the purpose of our annual service review. She was going to write up the plan we discussed and get it to me the following week to review and sign. As of today, 5/4/24, we have not heard anything or received any emails.”*
6. *“When visiting a CILA with a group of interested families, the following were concerning to us on many levels. It was exactly like an institution disguised as a CILA and day workshop. There was no person-centered planning and they were warehousing individuals.*
 - *Five women were living in a small house with a small kitchen table and only four chairs.*

- *There were locks on the cabinets and assigned times for bathroom use.*
 - *Residents had to leave the house by 7:30am every day. When asked what would happen if someone was sick, we were informed that the ill person would have to be sent to a home that house sick individuals of the day from the area's CILAs.*
 - *At the workshop, individuals looked bored, and most were sitting at tables doing nothing. Some individuals had a job for the day which was putting stoppers and rings on water bottles. As there was not enough "work" they rotated who got to work and who sat all day long."*
- *"My 30-year-old son was diagnosed with Lennox-Gastaut Syndrome at the age of 2. He is mobile, has limited communication, and needs assistance with most ADLs. He is cooperative and has no behavior challenges but is slower than most and may fall asleep during the day. He has been rejected by community day services due to his need for 1:3 ratio support. In 2011, we started at 1:3 private pay community-based day program with five other families and my son has been attending for thirteen years. He also attends a 1:3 Rec & Roll once a week. Since neither program is licensed by IDHS, he would not be able to attend either of them if he were to move to a CILA. We have been pursuing CILA placement for 5 years. His packet has been sent to over 50 agencies with 8 rejections after an initial screening and 2 after weekend visits. The only agency we said no to offers a "CILA" home on an ICF/DD campus 1.5 hours away from our home in a rural community. Is this the level of isolation we must accept as reasonable? I asked our ISC about the Housing Navigator. While this service is communicated as being available to everyone, we were told it is not available to individuals who need 24-hour support."*

These testimonials provide a clear picture that is in stark contrast to national best practices as Illinois continues to rely heavily on SODCs, ICF/DDs, sheltered workshops, and 6-8 resident CILAs. To further illustrate, in their Memorandum in Opposition to Defendant's Motion to Terminate the Consent Decree, Plaintiffs included a declaration from Annette Downey, Chief Executive Officer of

Community Living Services, one of the largest non-profit agencies in Michigan which supports over 5,000 individuals of all ages with physical and intellectual and developmental disabilities (I/DDs). Ms. Downey stated in this declaration, “It is well known that Illinois is a state that serves some of the highest numbers of people in institutions. It is not that families and individuals with I/DD are any different in Illinois than other states. It is merely a reflection of how people with I/DD are valued in a state by those who make decisions on whether or not to invest in best practice models in line with human rights and all that this profession stands for.”

Since implementation of the Consent Decree, the Monitor has reviewed and analyzed copious data and reports to assess Defendants’ efforts toward compliance and maintenance. The following reflects the Monitor’s opinion and rationale for determination on the status of compliance with the Decree regarding issues of significant concern. However, it should not be construed that the Monitor has determined the Defendants are in compliance with other areas of the Decree as additional time and information is required for a thorough assessment.

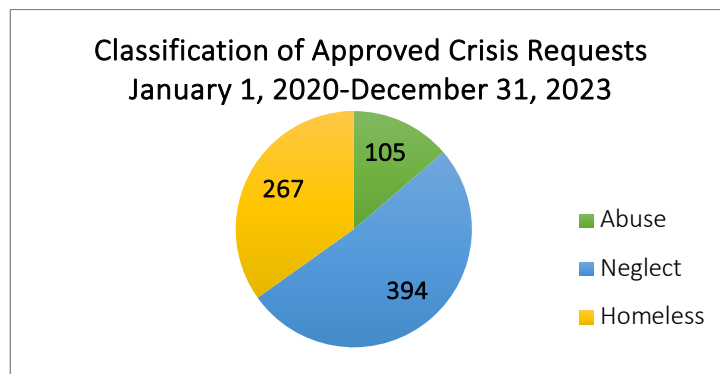
Resources and Timely Authorization of Funding for Class Members in Crisis

As indicated in Paragraph 21(a)-(b) of the Ligas Consent Decree, “an individual is in a situation of “Crisis” if he or she is at imminent risk of abuse, neglect, or homelessness. The provision of interim emergency services (including interim placement in an ICF-DD where no placement in a Community-Based Setting was immediately available) will not necessarily exclude the Individual from being deemed to be in a situation of Crisis. If, following a screening, the Individual who is

determined to be in Crisis requests appropriate Community-Based Services to be provided in the Family Home or requests placement in a Community-Based Setting, Defendants will promptly develop, in conjunction with the Class Member, a Transition Service Plan.”

State Defendants are required to serve expeditiously Class Members who meet the above-described criteria and who request community services or placement in a community-based setting. During the 2013/2014 reporting period, the Monitor established, with the agreement of the parties, that the timeframe to receive services for Class Members in crisis will be 24-72 hours, although this timeframe may vary, depending on individual circumstances, or if temporary services are in place to address the immediate crisis. Since this agreement, the Monitor has analyzed class member information and data from all crisis requests received and reviewed by the Defendants and has noted continued improvement with timeliness of review as required by the Consent Decree.

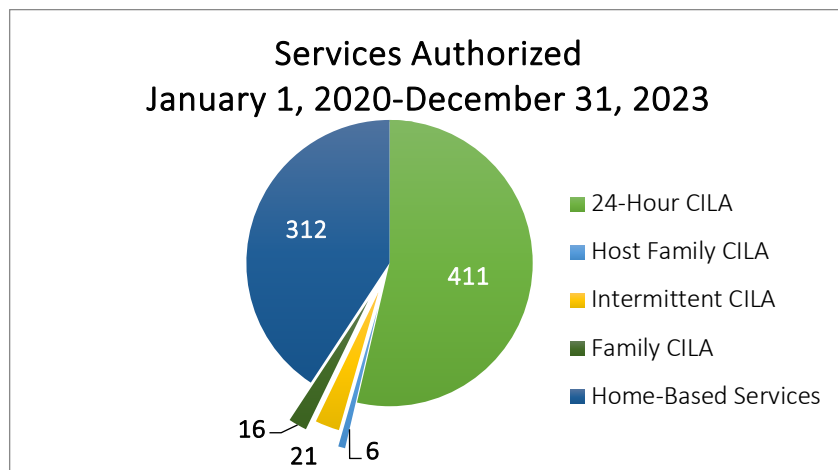
A review of data from January 1, 2020 through December 21, 2023 indicated that DDD approved 766 crisis funding requests: 105 were classified as abuse, 394 were classified as neglect, and 267 were due to the individual being homeless.



As can be seen in the chart below, the timeliness of review occurred, for the most part, within the 24-72 hours as established:

Timeliness of Review			
Within 1 day		700	91%
Within 2-3 days		44	6%
4-6 days		16	2%
7 days or more		6	<1%

Data also reflected that 77% of the Class Members who were authorized to receiving crisis funding were provided a service within a 24- to 72-hour period after their crisis status was confirmed. Services provided included four types of CILA (Community Integrated Living Arrangement) options: 24-Hour CILA, Host Family CILA, Intermittent CILA, and Family CILA, in addition to Home-Based Support Services (HBS). It should be noted that beginning January 2023, Family CILA and Home-Based Support Services were merged into one funding stream. Of the 766 approved crisis funding requests, 411 were funded to receive 24-Hour CILA, 6 were funded for Host Family CILA services, 21 were funded to receive Intermittent CILA, 16 were funded to receive Family CILA, and 312 Class Members were authorized to receive Home-Based Support Services.



However, it should be noted that the data provided to the Monitor reflected 16 instances where the date service began was prior to the date the region received the crisis funding packet for review. Therefore, the data was misleading in that funding was not authorized timely as a result of the crisis funding request process. Examples included¹:

- *Trade Industries is offering Class Member #41 immediate placement. He will remain there until funding is approved.*
- *Class Member #62 is on a visit with Pathway. Pathway has accepted him and he will remain there until his funding packet is processed.*
- *Class Member #147 and her grandmother got into an altercation which resulted in her being kicked out of the home. The police tried to take Class Member #147 back to her grandmother's home but the grandmother refused. Class Member #147 stayed overnight at the police station. MCHC agreed to pick her up the next day on an extended visit pending eligibility and approval of funding.*
- *Class Member #190's grandmother/guardian had a medical emergency and was in a coma. The doctors stated that even when she awakens, she will not be able to provide her needed care. Class Member #190 was admitted to Decatur Memorial until CILA placement is secured.*
- *Class Member #489 was taken to a homeless shelter where he will remain until funding is in place.*
- *Class Member #740 will remain hospitalized until funding is approved.*

The Monitor has repeatedly raised concerns about these temporary safety plans for a number of years and the adequacy of crisis safety plans remains significantly deficient. Following are examples from the crisis funding requests received between 1/1/23-12/31/23. In these situations, the temporary safety plan did not indicate that the Defendants secured interim emergency services for the individual in crisis, but rather accepted situations where family members, friends, or neighbors would check on the individual, temporary housing situations, or hospital and long-term care admissions as allowable substitutions until services could be authorized and initiated:

- *Class Member #6 will remain in her family home with her cousin checking in on her.*

¹ Individual names have been redacted and replaced with a coded number.

- *Class Member #43 has been residing at Lurie's Children's Hospital since September and will remain there until residential services are initiated on 11/21/23.*
- *Class Member #62 is on a visit with Pathway House and has been accepted for services. He will remain there until his funding packet is processed.*
- *Class Member #81 is admitted to Rush Hospital and will remain until he transitions to a CILA.*
- *Local area churches have secured an Airbnb for Class Member #84. He will then go to Patterson House on a visit and stay until funding is approved.*
- *Class Member #89 is inpatient at Robert Young Center until funding can be secured. (Note: services for lass Member #89 did not begin as she chose to remain at a mental health facility.)*
- *Class Member #106 will continue to stay at Gateway Regional Medical Center in the Older Adults Behavioral Unit until placement is found.*
- *Class Member #171 will remain at the shelter until CILA services begin.*
- *Class Member #194 has his own cell phone and with support from his uncle can make doctor appointments. He has the money to temporarily stay in a hotel while looking for an apartment.*
- *Class Member #224 stayed in a hotel until he went on an extended visit at Abundant Possibilities where he will remain until funding is in place.*
- *Class Member #397's family is private paying Center for Independent Futures to provide services until funding is in place.*
- *Class Member #421's aunt will care for him in her home during the weekdays. A cousin will monitor him electronically on weekday evenings and overnights. The cousin will provide care for him in her home on weekends. Neighbors will help keep an eye on him and will alert the cousin or 911 if there are any issues.*
- *Class Member #448's sister is assisting in finding him temporary housing or an Airbnb and she contacts him daily or travels back and forth from Wisconsin. He also receives life coaching from Monarch Services to help him with medications, grocery shopping, and appointments.*
- *Class Member #527 will remain in the nursing home until services begin.*
- *Class Member #570's father took a leave of absence from work until services are in place.*
- *Class Member #682's family has installed cameras for communication when his mom is at work. His siter checks on him throughout the day.*

The foregoing analysis of crisis data that has been reported annually by the Monitor since 2014 reflects only those individuals whose Crisis Transition Plan and Funding Request had been accepted and approved by the Defendants to authorize funding. This information analyzed and reported by the Monitor in previous reports did not reflect numerous other

individuals who had been determined to be in crisis but had not received crisis funding as the Independent Service Coordinator agency had not secured a provider prior to submitting the Crisis Transition Plan and Funding Request. The Defendants issued a report to the Monitor and Plaintiffs in June 2023 that reflected tracking of 100 individuals who had “raised their hands” in crisis (53 of whom were indicated as being in the Ligas Class Member database). The Defendants have continued to provide monthly updates on people who have raised their hands but not allowed to apply for crisis services, the most recent reflective of data through March 2024. The Monitor compiled these reports into one cumulative report which now includes over 360 individuals in some type of crisis situation (between May 2023 and January 2024)². These individuals have neither been allowed to apply for crisis funding nor have received expedited funding from the Defendants (many noted to have been waiting in excess of 100 days). Two individuals from this list identified as Ligas Class Members were admitted to a SODC.

Numbers alone cannot reflect the dire situation of individuals needing crisis funding, but the following case vignettes show the plight of individuals awaiting services and clearly illustrate why expeditiously was defined as within 24-72 hours:

- *Class Member #968 was in Riveredge Hospital’s psychiatric unit from the beginning of October through the end of February. He was admitted to the hospital for attempting to sexually aggress towards staff (many times and verbalizing he would do it again). When brought to the hospital, his provider refused to pick him up and served an immediate discharge notice. The ISC appealed the discharge, however the provider was never required to pick him up or continue to serve him. The ISC searched statewide for a provider and did not find one. He could not go to a Short-term Stabilization Home (SSH) because he did not have a provider committed to serving him. At that point, a SODC was agreed upon by DDD. However, to be admitted to the SODC the guardianship papers had to be amended to include the terminology “power to place.” This took several months. When the guardianship paperwork was amended, he was then placed into the Shapiro SODC.*

² The Monitor has concerns with the validity and reliability of this monthly data with regard to whether individuals in the report are Ligas Class Members and the dates provided reflecting notification of crisis and current status, as well as whether the individual received Medicaid waiver funding and the type of funding, and if not, what is being done to secure funding.

- *In mid-September 2023, Class Member #420's mother attempted to drop her off at a hospital because she could no longer provide care. The hospital refused to take her in and called Adult Protective Services. The ISC contacted the mother to initiate the process of finding supports in order to request crisis funding. The ISC contacted DHS-DDD and reported the family's circumstances and need for crisis funding. The ISC offered Home-Based Services but the mother stated she has no one to work if the service was provided. Class Member #420's mother signed consents for a statewide search for CILA providers with openings. Straightaway, 43 providers refused to serve Class Member #420 and numerous others did not respond. Repeated searches resulted in more rejections due to her PICA behavior and other physical and behavioral support needs. This continued through November when on 11/28/23 a provider in Springfield agreed to provide services and a Crisis Transition Plan was developed and a funding packet submitted for authorization. Class Member #420 moved to her new CILA home on 11/30/23.³*

Per the Ligas Consent Decree, Section III.3(e)-(f) "Community-Based Services" means those services (other than a placement in a Community-Based Setting) available under the Waiver. "Community-Based Setting" means a Waiver-funded residential setting with a maximum of eight (8) beds, but does not include an ICF-DD, that is the most integrated residential setting appropriate for an Individual where the setting is designed to promote independence in daily living, community integration, and economic self-sufficiency and enables the Individual to interact with non-disabled persons to the fullest extent possible.

Per the Ligas Compliance Evaluation Standards (July 17, 2012) Crisis Services Requirement, "The provision of interim emergency services (including interim placement in an ICF-DD where no placement in a Community-Based Setting was immediately available) will not necessarily exclude the Individual from being deemed to be in a situation of Crisis. If,

³ In this case, Class Member #420 was included in the crisis data provided to the Monitor which reflected that the DHS-DDD region received the Crisis Transition Plan and Funding Request on 11/30/23 and authorized services to begin on 11/30/23. The Temporary Safety Plan for Class Member #420 indicated "[Class Member #420] will remain in her mother's home with increased assistance from [Individual 420]'s brother, sister-in-law, and sister until CILA placement can be secured." This statement was not factual nor did the dates provided in the report accurately reflect Class Member #420's situation.

following a screening, the Individual who is determined to be in Crisis requests appropriate Community-Based Services to be provided in the Family Home or requests placement in a Community-Based Setting, Defendants will promptly develop, in conjunction with the Class Member, a Transition Service Plan. Defendants shall ensure that all Class Members who are determined to be in a situation of Crisis, and who request to receive Community-Based Services and/or placement in a Community-Based Setting, receive such services and/or placement in such setting expeditiously⁴.”

It is the Monitor’s opinion that Defendants have not met their obligations to expeditiously provide services to Class Members in crisis and are not in compliance with the Ligas Consent Decree.

Ligas Class Members Residing in SODCs

Defendants are continuing to place Class Members in SODCs. Data was initially provided to the Monitor in March 2021 and Defendants have continued to provide updated data to the parties with the most recent being March 31, 2024. This database included 599 individuals admitted to SODCs from 2017 to present; 200 of whom were identified to be Ligas Class Members currently residing in six of the seven SODCs.

SODC	# of Class Members
Choate	104
Kiley	11
Ludeman	10
Mabley	8
Murray	32
Shapiro	35

⁴ Ligas V. Hamos - Compliance Evaluation Standards July 17, 2012, 14 Area of Compliance – Crisis Services Requirement – Class Members who meet the crisis criteria described in ¶21 (a) of the Decree and who request community services or placement in a community-based setting expeditiously. Services and/or placement will be provided in a manner consistent with the transition plan. Deadline/Timeframe – Community-based services or placement in a community-based setting will begin expeditiously so as to effectively alleviate the crisis and maintain safety, health and stability. The expected timeframe for services to be in place for Class Members in crisis will be 24-72 hours, although this timeframe may vary, depending on the individual circumstances, or if temporary services are in place to address the immediate crisis. Implementation Plan Activities – The Implementation Plan calls for the PAS/ISC agencies to continue to submit requests for services from individuals in crisis situations. DDD will ensure that Class Members are served expeditiously.

The following chart provides a breakdown of where Class Members were residing prior to admission and the reason for admission to a SODC:

Admitted From:	# of Class Members	Reason for Admission
Children’s Group Home	6	4=provider closed 2=aged out of services/no provider located
CILA	84	36=behavior 5=court ordered/judicial 1=home closed 2=CILA provider discharged individual/no alternative and appropriate provider was located located/identified 5=individual choice/voluntary 6=emergency placement/inappropriate provider discharge 5=behavioral/medical–ISC supported immediate transfer 17=discharge, no appeal filed 4=discharge, provider discharge upheld 2=medical 1=evaluation
Home/Homebased	42	12=behavior, medical 1=behavioral/medical–ISC supported immediate transfer 10=court ordered/judicial 8=no provider located/identified 11=individual choice
Hospital	18	5=behavior 1=medical 3=court ordered/judicial 1=emergency placement/inappropriate provider discharge 8=no provider located/identified
ICF/DD	11	3=behavior 3=court ordered/judicial 2=discharge, no appeal filed 3=home closed
Jail	4	1=behavior 3=court ordered/judicial
Mental Health Facility/ Psychiatric Hospital	10	5=behavior, medical 2=behavioral/medical–ISC supported immediate transfer 1=court ordered/judicial 2=transfer
SODC	14	2=behavior 11=transfer 1=guardian placement
SODC-Forensic	7	7=court ordered
Other	4	2=behavior 1=transfer 1=evaluation

From this monthly report, placement status for 145 (73%) of the 200 Ligas Class Members residing in SODCs was noted to be “guardian will not agree to placement” while 54 guardians

were noted to be currently looking for alternate placement.

The Monitor requested a sample of Individual Support Plans (ISPs) for 31 of the Ligas Class Members residing in SODCs to assess transition planning efforts to support Class Members to live in a less restrictive, more integrated setting. Review of the ISPs revealed that 3 Class Members had transition goals to transfer to a different SODC. Sixteen Class Members had expressed a desire to move to the community, yet for the most part, their transition goals were based on continued placement in the SODC such as increased independence and socialization skills; have access to the community and interact with people in community settings; decrease maladaptive behaviors; or to obtain employment either on or off campus. Although individuals residing in the SODCs had an annual ISP, the transition planning component within that plan was insufficient to meet the requirements set forth in Section VII, paragraphs 10-16 of the Consent Decree. Seven Class Members of the thirty-one reviewed had an ISP that included a desired goal to transition to the community. However, the likelihood of realizing their desired goal to live in a less restrictive setting would not occur without adequate community supports and resources:

- *Class Member #4 was admitted to Kiley SODC in February 2021 from a hospital where he had been since 12/6/20. His most recent ISP (1/25/24) reflected that he stated he would like to explore community placement in the next year and his guardian stated she wanted him to move to the community so he could move into a new house and make new friends. The transition goal developed by his Interdisciplinary Team (IDT) indicated was by 1/31/25, Class Member #4 will have transitioned to living in a CILA of his choice with 1-2 roommates to further increase his independence.*
- *Class Member #9 was admitted to Kiley SODC in July 2021 after the children's home where he was residing closed. His most recent ISP (7/20/23) reflected that he mentioned he would like to return to the CILA with his friends. His guardian stated she felt he had benefitted from living at the SODC and was ready for him to transition into community living. The transition goal developed by his IDT was by 7/31/2029, Class Member #9 will live in a community residence that will provide supports and services commensurate with his identified preferences.*
- *Class Member #12 was admitted to Choate SODC in October 2021 after his CILA provider discharged him. His most recent ISP (9/26/23) reflected that he expressed a desire to return to the community and missed living in the community and that he was being provided education by the IDT on available*

homes within the community. He had attended the provider fair at the SODC. His mother had requested to no longer be his guardian and a transfer of guardianship was made to the Office of State Guardian (OSG). The ISP indicated that once this transfer was complete the IDT would work with his guardian and ISC to begin pursuing transition planning. His desired goal was to live in a CILA home in the community.

- Class Member #18 was admitted to Mabley SODC in September 2022 for emergency placement following an inappropriate discharge from her CILA provider. Her current ISP (5/11/23) reflected that she had expressed a desire to move out of the SODC for several years. Her guardian stated a desire for Class Member #18 to be happy and have every opportunity to live in the community if she wanted to do so. The transition goal developed by her IDT was Class Member #18 will be placed in a small CILA by 2026.
- Class Member #26 was admitted to Ludeman SODC in February 2023 from a hospital after being discharged from his CILA provider. His current ISP (2/29/24) reflected that he had expressed he would like to one day reside in a CILA or a group home with increased independence. His guardian would like for him to transition to a less restrictive environment that will help him gain independence in the community. The transition goal developed by his IDT was Class Member #26 would like to discharge to a CILA by 2025 and gain willful employment.
- Class Member #29 was admitted to Kiley SODC in November 2023 after being discharged from his CILA. His current ISP (11/21/23) indicated that he was motivated to move to a community residential setting and was seeking opportunities to discuss with his IDT. His guardian indicated that she will revisit his transition status. The transition goal developed by his IDT was by 11/30/29, Class Member #29 will live in a home in the community with the supports to meet his presenting needs and preferences and in a location that will facilitate family visits.
- Class Member #31 was admitted to Shapiro SODC in December 2023 after being moved from his home with his family to a hotel on a temporary emergency placement. His ISP (12/28/23) indicated that he had not expressed an opinion about exploring other places to live, but his guardian stated they would like for him to move to a CILA home in Quincy, IL as soon as possible. The transition goal developed by his IDT was for Class Member #31 to move to his chosen home in Quincy, IL by 11/28/24.

A highly publicized account of a Class Member residing in Kiley SODC was that of Kaleigh Rogers in an article titled “In Crisis, She Went to an Illinois Facility. Two Years Later, She Still Isn’t Able to Leave.”⁵

Kaleigh Rogers was in crisis when she checked into a state-run institution on Illinois’ northern border two years ago. Rogers, who has cerebral palsy, had a mental health breakdown during the pandemic and was acting aggressively toward herself and others.

⁵ Parker, M. & Hundsdorfer, B. (2024, February 8). In crisis, she went to an Illinois facility. Two years later, she still isn’t able to leave. *ProPublica*. <https://www.propublica.org/article/illinois-crisis-institution-placement#:~:text=Kaleigh%20Rogers%20was%20in%20crisis,aggressively%20toward%20herself%20and%20others.>

Before COVID-19, she had been living in a small group home; she had been taking college classes online and enjoyed going out with friends, volunteering and going to church. But when her aggression escalated, she needed more medical help than her community setting could provide.

With few viable options for intervention, she moved into Kiley Developmental Center in Waukegan, a much larger facility. There, she says she has fewer freedoms and almost nothing to do and was placed in a unit with six other residents, all of whom are unable to speak. Although the stay was meant to be short term, she's been there for two years.

The Ligas Consent Decree mandates that individuals will receive services, programs, and activities in the most integrated setting appropriate to their needs. DDD contracted with the Institute on Disability and Human Development (IDHD) at the University of Illinois Chicago (UIC) to conduct a number of analyses of transitions out of the seven State-Operated Developmental Centers (SODCs) in Illinois. The most recent analysis covers transitions out of SODCs between July 1, 2016 and June 30, 2022.⁶ The resulting [report](#) from July 2023 provided detailed information on the types of residential settings individuals transitioned to from SODCs in the period analyzed, noting specifically:

- *Of the 527 live transitions, slightly less than a third (30.7%) went to CILAs, or community-integrated living arrangements (both intermittent CILA, or I-CILA, and 24-hour CILA), 26.2% went to skilled nursing facilities (SNFs), 10.4% went to family settings, 9.1% went to another SODC, 8.9% went to jail, 4.6% went to an intermediate care facility for developmental disabilities (ICF/DD), 4.4% went to a state-operated mental health center (MHC), and 5.7% went to another setting. (pg. 3)*
- *The percentage of transitions to CILAs peaked in FY19 (37.0%). The percentage of transitions to an ICF/DD decreased across the years, with no transitions to an ICF/DD in FY22. Transitions to SNFs dropped in FY20 (from 24.4% in FY17 to 9.4% in FY20), then increased again in FY21, and peaked in FY22 (38.6%). The percentage of transitions to other SODCs (9.0% vs.18.8%) and family homes (7.7% vs. 16.5%) increased two-fold from FY17 to FY20. (pg. 3)*
- *Almost two-thirds (64.4%) of people who transitioned had at least one psychiatric diagnosis. The percentage of people transitioning with a psychiatric diagnosis increased from FY17 to*

⁶ Crabb, C. Hsieh, K., & Heller, T. (2023). *An analysis of movement from Illinois state-operated developmental centers: Transitions between July 1, 2016 – June 30, 2022*. Chicago: Institute on Disability and Human Development, University of Illinois Chicago. [7/1/2016-6/30/2022](#)

FY22 (from 48.6% to 69.7%) and indicated a statistically significant ($p = .005$) change across the six fiscal years. (pg. 3)

- Those transitioning to community settings (CILA and family settings), were generally younger (CILA: 41.3 mean age and family: 36.1 mean age) compared to ICF/DDs and SNFs (ICF/DD: 60.3 mean age and SNF: 63.7 mean age). People in community settings (CILA and family settings) had lower health risks, especially compared to those in institutional settings like ICF/DDs and SNFs. People transitioning to ICF/DDs and SNFs had the highest health risks, lowest average ICAP Service Level scores (indicating more support needed), and the lowest average IQs. People who had been in SODCs the longest generally transferred to institutional settings including ICF/DDs and SNFs. (pg. 4)
- Of the 479 transitions from a SODC to a non-SODC setting, 96 returned to a SODC (20.0%). The main reason for return (for those that were not missing a return reason, $n = 94$) was behavioral (36.2%), followed by other (24.5%), short-term therapy (21.3%), and medical (18.1%). (pg. 4)
- Of the returns to a SODC from a CILA, all did so because of a behavioral reason. (pg. 4)
- Compared to those who maintained community placements, individuals who returned had significantly lower ICAP Maladaptive Behavior Domain scores (with the exception of the Asocial score, which was lower for returners, but not significantly). (pg. 6)

The report further indicated:

Interpreting these themes without further research should be done with caution. The themes suggest that more individuals with more significant behavioral support needs are difficult for community providers to support, which is consistent with previous anecdotal evidence.⁷ In FY22, DDD contracted with UIC's IDHD to create a report assessing the Illinois DD system's capacity to serve individuals with significant or specific support needs. The intent of this work was to understand who is offering these supports in the system, identify providers who could serve as models on specific support needs, and identify ways to expand the capacity of the State to provide these supports to people with IDD. The report included a number of recommendations for DDD to support community capacity for people with IDD and specific support needs, including those with behavioral support needs and ASD. The stabilization home program was approved to expand in Illinois' FY24 budget. (pg. 28)

Perpetual funding challenges plague Illinois and the country in the provision of supports for people with IDD. In August 2017, a rate study was initiated by DHS-DDD in response to Judge Sharon Johnson Coleman who declared Illinois out of compliance with the Ligas Consent Decree. More specifically, the judge cited low quality of services primarily as a result of low wages for direct support professionals (DSPs). As a step toward coming into compliance with the Ligas Consent Decree, an external consultant, Guidehouse (formerly

⁷ Crabb, C., Heller, T., & Hsieh, K. (2022). *An evaluation of community capacity barriers and opportunities for expansion in Illinois for adult DD waiver services.* <https://www.dhs.state.il.us/page.aspx?item=144695>

Navigant) was hired. The report was completed in the fall of 2020 and included key recommendations. The FY2022 budget for DHS-DDD included an additional \$170 million (partly through the American Rescue Plan), the highest-ever investment in the DD system in Illinois. DHS-DDD plans to use this money to permanently implement some of the Guidehouse rate study recommendations. One recommendation related to the pay for DSPs. The FY24 Illinois budget included a \$2.50/hour increase for DSPs providing supports in the community and in ICFs. pg. 28 (of 7/1/2016-6/30/2022 report)

A previous evaluation⁷ recommended that the data analysis supported “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.”

It is the Monitor’s opinion that Defendants are not in compliance with providing adequate services to Class Members with higher support needs in the least restrictive, most integrated setting.

Reasonable Pace and Timely Authorization of Services

Defendants have not fully complied with their reasonable pace obligation that ensured by fiscal year 2025, no class member will wait longer than 5 years (60 months) from their enrollment on PUNS to the time they receive services. The data clearly shows a sluggish situation. Data reflected that 1,342 Class Members were selected from the PUNS list in July 2023, but as of March 2024, not even 25% have received services, leaving 1,108 still waiting to be served. Even when Class Members are selected from PUNS the time it is taking to get them into services far exceeds the reasonable pace expectation. Looking at PUNS list as of March 2023, a total of 10,320 Class Members have been selected since implementation

⁷ 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 Chicago. [7/1/2016-6/30/2020](#)

of the Consent Decree, and yet 2,646 are still waiting 60 months or more to receive services.

Additionally, the Monitor requested data for all Ligas Class Members, their PUNS selection date, and date services were initiated between 2012 and 2023. The Defendants provided a list with over 7,000 Class Members who had been selected from the PUNS list and who were noted to have services initiated. When the Monitor asked for how the Defendants verify that services were initiated, the response received was:

“Services initiated” is a date that is reported to us from the ISCs. That is the date the ISC says they started whatever service they entered. We call them “services Initiated” at that point. The Reasonable Pace Proposal defines entering services as, “those who have begun receiving services under the Waiver (Home-Based or CILA), as reported by the ISCs.”⁸

The Defendants contract with Independent Service Coordinators (ISCs) as the entity all Class Members must utilize to access Medicaid waiver HCBS services. While Defendants are ensuring individuals are selected from the PUNS list at an increasing rate, ISCs reported to the monitor that their resources have not been sufficiently compensated to keep up with the workload and to hire additional staff to provide the coordination of services. Therefore, Class Members’ wait is not over after being selected from the PUNS; they are yet again “waiting” to receive the services they waited so long to receive in the first place.

ISC agencies reported to the Monitor that they have been forced to create internal waiting lists for individuals to even be assigned a service coordinator to help Class

⁸ Again, the Monitor questions the reliability and validity of data being produced for determination of compliance.

Members obtain services once selected. And, ISC agencies have requested additional funding from the Defendants, but have not received the resources for what is required to meet the need.

Illinois HB5762, introduced in March 2024 by State Representative Ness, proposes an appropriation of \$20.3 million from the General Revenue Fund to the Department of Human Services for Independent Service Coordinators in Illinois. However, it is unclear if this amount (or any additional funding for ISCs) will make it into the final budget bill. Due to state budget woes, one State Representative indicated it was not likely to be incorporated into the final budget bill this year.

In the spring of 2021, DDD contracted with IDHD at UIC to evaluate the person-centered planning process and make recommendations to improve the process. As part of this evaluation, the Division tasked UIC with better understanding how the State may better support seven different groups of people with IDD and additional support need. The intent was to adequately support these groups and identify ways to expand the capacity of the State to serve these groups of people with developmental disabilities. The groups identified were:

- People with complex medical support needs
- People who are insulin-dependent diabetics
- People with high behavioral support needs
- People with autism spectrum disorder or other sensory support needs
- People who are deaf/hard of hearing
- People who are blind/have a visual impairment
- People who have physical accessibility support needs

Individual interviews along with online surveys of the DD provider community were conducted to better understand the barriers to serving these seven groups of people with DD to develop the survey, and to identify strategies to increase provider capacity.

Recommendations included:

- Specialized training of direct support professionals (DSPs)
- Premium pay for DSPs who support these different groups
- Employment of certain professionals on staff rather than on a contractual basis, such as nurses recommendations
- Increase salaries for certain staff to address the staffing shortage
- Implement environmental adaptations to address physical and sensory needs
- Ensure that ISCs (Independent Service Coordinators) are assisting individuals in accessing non-waiver services that they may be eligible to use
- Address provider liability concerns by supporting providers to better understand and problem solve dignity of risk situations
- Allow for more flexibility in the rate structure for individuals with more support needs and to address person-centeredness

It is the Court Monitor's opinion that the Defendants are not in compliance with reasonable pace and timely authorization of services.

Assessing Quality of Supports Provided in CILAs

Paragraph 4 of the Consent Decree states that “Defendants shall implement sufficient measures to ensure the availability of services, supports and other resources of sufficient quality, scope and variety to meet their obligations to such individuals under the Decree and the Implementation Plan consistent with such choices.” The Court’s order of June 6, 2018 recommended the development of a monitoring tool, “with an independent review component” to assess adequacy of

services. With this justification, the Monitor conducted a review of 225 Class Members in 2019⁹.

A second round of compliance reviews of 215 Class Members was conducted beginning with a pilot week in November 2022 and continued through mid-May 2023 by a team comprised of representatives from UIC, the Bureau of Quality Management (BQM), and those selected by the Monitor.

As was the process following the 2019 Ligas Compliance Monitoring reviews, individual scorecards and findings for Class Members reviewed were issued to each ISC, CILA, and Community Day Services (CDS) provider for whom they are responsible. Each provider was required to develop a Plan of Corrective Action (POCA) to address each domain that received an overall rating below 85% as well as any "Not Met" red flag and HCBS Settings Rule measures in domains greater than 85%.

POCAs from all ISC agencies and most CILA/CDS providers were received and reviewed by the Monitor and Program Manager. Each POCA received a rating of Accepted, Provisionally Accepted (no re-submission required), or Not Accepted (returned for revision). For those rated as Provisionally Accepted, the Monitor did not require a written revision, but corrective actions were to be clearly identified and implemented. For POCAs rated Not Accepted, it was determined that in one or more areas, the plans were not sufficient to remedy the deficits that led to the "not met" ratings. From the 2019 Compliance Review, approximately 22% of the POCAs

⁹ 7th Annual Report of the Court Monitor

submitted by ISC agencies and 14% of those submitted by CILA providers were rated Not Accepted and thus required re-submission.

From the 2022-2023 Compliance Review, Individual Tools and Scorecards were submitted to providers for development of POCAs. Numerous providers were contacted multiple times by UIC and DDD as they had not submitted their corrective action plans by the deadline. From the 2022-2023 Compliance Review, approximately 39% of the POCAs submitted by ISC agencies, 50% of those submitted by CILA providers, and 22% of those submitted by CDS providers were rated Not Accepted and thus required re-submission.

A comparison of ratings from the 2019 Compliance Measures Review and the 2022-2023 Compliance Review indicated some progress was noted in several areas, especially those where HCBS Settings Rules apply. However, areas such as employment and community integration that impact the overall quality of life of Class Members in terms of stability in their CILA homes and success in their daily community life remained deficient. Two areas that saw slight improvement were behavioral and mental health supports and services. A decrease in performance was noted in the areas of physical and occupational therapy, speech-language and other communication supports and services. The two critical areas of Person-Centered Planning and Independent Service Coordination also remained deficient.

Person-Centered Planning forms the foundation for the outcomes that the person desires in their life; what is important to the person; ensures personal preferences, health, and welfare; and addresses risk factors with supports and strategies to

minimize the identified risks. The Person-Centered Plan, called the “Personal Plan” in Illinois DD services, also provides the justification for the services provided and expectations for service monitoring and quality evaluation by ISCs.

DDD contracted with UIC’s IDHD to evaluate the person-centered planning process in Illinois. From that project came a number of recommendations, some of which have already been implemented by the Division (e.g., standardize the Implementation Strategies form for providers). Other recommendations have not been fully addressed and could significantly improve the person-centered planning process. Thus another example of where Defendants do not fully follow through and implement necessary systemic change.

The Defendants have also argued that the Monitor’s acceptable compliance standard of 85% is unreasonable and have taken a position that they are in substantial compliance regarding the adequacy of services and supports provided to Class Members living in CILAs. Given the results of the most review, while there was some improvement, it should not be assumed that Defendants have achieved substantial compliance nor that Defendants can show sustained compliance after only two rounds of external reviews. Defendants agreed to adopt portions of the Ligas Compliance Measures into their existing Bureau of Quality Management tool and process. The Monitor requested aggregate data from these reviews to assess performance on the adopted measures, but none was provided, and it was reported to the Monitor that such data is not collected. Therefore, additional information is necessary to determine if the Defendants’ reviews of providers

supporting Ligas Class Members yield acceptable performance outcomes over time.

It is the Monitor's opinion that Defendants are not in compliance with ensuring the availability and adequacy of services and supports provided to Class Members.

Conclusion

The Court Monitor has issued numerous reports and briefs at the request of Magistrate Judge Cole relative to Defendants efforts to comply with requirements and compliance status with the Consent Decree. It is the Monitor's opinion that Defendants have not provided satisfactory evidence that the objectives of the Decree have been achieved.

The Decree requires "Substantial Compliance" and a showing that the Defendants have "implemented and maintained a system that complies with the Decree." Paragraph 49 of the Decree specifically states that the Court will grant Defendants' Termination Request and terminate the monitoring process if the Court finds that Defendants have substantially complied with the terms of the Decree and Defendants have implemented and are *maintaining* a system that complies with the Decree.

It is the Court Monitor's opinion that the Defendants have not satisfied this requirement.

Paragraph 50 of the Decree states that termination of the Court's jurisdiction over the Decree may occur only in the event of a successful request to terminate the monitoring process pursuant to Section XVIII.

It is the Court Monitor's opinion that the Defendants have not presented a successful request to terminate.