

**UNITED STATES DISTRICT COURT  
NORTHERN DISTRICT OF ILLINOIS  
EASTERN DIVISION**

STANLEY LIGAS, et al.,

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Plaintiffs,

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vs.

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No. 05 C 4331

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FELICIA NORWOOD, in her official  
capacity as Director of the Illinois  
Department of Healthcare and Family  
Services, et al.,

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Judge Sharon Johnson Coleman

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Defendants.

**FOURTH ANNUAL REPORT OF THE MONITOR**

# Stanley Ligas, et al. v. Felicia Norwood, et al.

## Fourth Annual Report of the Monitor

January 7, 2016

### **INTRODUCTION**

This report is respectfully submitted to the Court, the Parties and the Intervenors in accordance with the Ligas Consent Decree (Decree), which was approved and filed by the Court on June 15, 2011. The Decree requires that:

The Monitor shall file annual reports to the Court, which shall be served on all Parties and Intervenors and be made publicly available. Such reports shall include the information necessary, in the Monitor's professional judgment, for the Court, Plaintiffs and Intervenors to evaluate Defendants' compliance or non-compliance with the terms of the Decree.<sup>1</sup>

The first Ligas Monitor, Tony Records, was appointed by the Court on July 19, 2011. Upon his retirement, the current Monitor's appointment was effective on July 1, 2015. Mr. Records' generous sharing of his time and expertise during this transition has been invaluable to the current Monitor.

The first three Annual Reports of the Monitor were submitted by Mr. Records on September 27, 2012, September 30, 2013 and September 30, 2014. Based upon the timing of the current Monitor's appointment in July, 2015, the reporting

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<sup>1</sup> Consent Decree, ¶ 34 at page 19

schedule has been revised for this year to allow the Monitor six months for an initial evaluation of compliance with the terms of the Decree. The process of completing this Fourth Annual Report would have been significantly more difficult without the unfailing cooperation of the Defendants, Plaintiffs' counsel and representatives, counsel for the Intervenors, service providers, advocacy organizations, family associations and others too numerous to mention. Input from those protected by the Decree and their families was not only critical to the Monitor's initial education about this case but is also a barometer of the Decree's effectiveness at this stage of its implementation.

## CHALLENGES

The current Monitor's appointment coincided with the beginning of FY 2016 and the absence of a State budget for Illinois. Initial activities of the Monitor were thus necessarily related to participating in efforts to maintain funding for services provided to all of those protected by the Decree as well as for others who share services with them, as partial funding for any given service would have caused many providers to either close their doors or significantly decrease operations.

On June 30, 2015, United States District Judge Sharon Johnson Coleman signed an "Agreed Order to Maintain Compliance with Consent Decree" which summarized the issue at that time as follows:

This case is before the Court on the parties' Joint Emergency Motion to Approve Agreed Order. The parties have advised the Court that the State of Illinois has not yet passed a budget appropriation for the State Fiscal Year beginning on July 1, 2015 (the "FY 2016 budget"). In the absence of a FY 2016 budget appropriation, Defendants will continue to provide all programs, services and personnel required by the Consent Decree (Dkt. #549), including without limitation any Implementation Plans issued pursuant to Section XIII of the Consent Decree approved by this Court on June 15, 2011 (Dkt. #549). It is the position of the Illinois State Comptroller that, without an appropriation, the Comptroller does not have the authority to continue to make payments for services, programs and personnel that are necessary to maintain compliance with the Consent Decree unless specifically ordered to do so by the Court.

In order to maintain compliance with the Consent Decree, IT IS HEREBY ORDERED THAT:

1. Until the FY 2016 budget takes effect, the Comptroller shall continue to make all payments for all services, programs and personnel, at a level no less than the levels paid in Fiscal Year 2015, that are necessary to comply with the Consent Decree and Implementation Plans. This order shall remain in effect until the effective date of the FY 2016 budget.
2. On or before July 1, 2015, Defendants shall publish this Order by (i) posting it on the DHS website, and (ii) transmitting a copy of the Order to all personnel and to all contractors and providers of services under the Consent Decree, including without limitation any contractors or providers of services that received prior notice of a possible reduction in payments or the reduction in or termination of a contract as the result of delays in completing a FY 2016 budget appropriation, via

email where available and by such other additional means as the Defendants employ for communications to the foregoing persons and entities in their usual course of business.

Following negotiations and conversations among the Parties, Intervenors and Monitor, as well as input to the Monitor from countless individuals and their family members in addition to providers of day, residential and advocacy services, a Joint Motion by the Plaintiffs' and Intervenors' to Enforce Consent Decree and Agreed Order was granted and another order was signed by Judge Coleman, this time on August 18, 2015, which states, in part:

Despite the Consent Decree and the Agreed Order, on July 23, 2015, the State of Illinois sent letters to developmental disability providers informing them that the State will fund services only for Class Members under the Decree and not for any other Individual with Developmental Disabilities for whom funding is required under the Consent Decree, including Individuals with Developmental Disabilities living in ICF-DDs or CILAs who are not Class Members.

Citing violation of both the Consent Decree and the Agreed Order, Judge Coleman enumerated the deleterious effects, on both providers of services and Individuals with Developmental Disabilities, of the State's "failure to provide funding as required by the Consent Decree and Agreed Order" and concluded that "immediate relief is necessary". The 8/18/2015 Order sets forth detailed requirements for the Comptroller's timely payments "for all services, programs, and personnel during the State Fiscal Year beginning on July 1, 2015 ("FY 2016"), at a level no less than the levels paid in Fiscal Year 2015, for all Beneficiaries of the Consent Decree." The Order ends with: "This Order shall remain in effect until the State enacts a budget for FY 2016 or until further order of this Court" and a status hearing was scheduled for September 9, 2015.

Prior to the scheduled status hearing, on August 25, 2015, Plaintiffs and Intervenors filed an Emergency Joint Motion for Entry of a Rule to Show Cause when the State did not comply with the Court's Order of August 18, 2015 to make court ordered payments to service providers by August 21, 2015. A hearing was held on August 26<sup>th</sup>, immediately prior to these payments were initiated. Following that hearing, on August 31<sup>st</sup>, Plaintiffs and Intervenors requested that the Court order Defendants to provide to the Monitor information regarding which payments were being made, why others weren't being made and when payments could be expected. Judge Coleman's Order, dated September 1, 2015 requires, among other provisions:

If at any time the State believes that it may not be able to comply with any provision of Consent Decree or this Court's August 18, 2015 Order, the State must immediately bring the State's potential non-compliance to the attention of the Court, the Monitor, the Plaintiffs and the Intervenors before such non-compliance occurs.

The Order also requires:

The Illinois Department of Healthcare and Family Services, the Department of Human Services and the Illinois State Comptroller shall provide such information to the Court Monitor and at such intervals as she may from time to time request to enable her to evaluate and to advise the Court and the Parties regarding the State's compliance with the Consent Decree and the Orders entered by this Court.

At the Parties Meeting on September 17, 2015, it was reported by Defendants that all payments to providers of services to those protected by the Ligas Consent Decree were up to date; that the State will notify the Monitor, Plaintiffs and Intervenors if any delays in payments are anticipated; and that the State has every intention of complying with the Ligas Consent Decree. However, it was also noted that the fiscal situation in Illinois is getting worse on a daily basis as the State's expenditures exceed revenue. The Monitor requested monthly reports of

the status of such payments and the Defendants have been providing positive information monthly as well as at the Court's scheduled status hearings. The Monitor has provided to the Defendants an "Information Request Regarding Ligas Payments" to be used in the event that noncompliance is anticipated by the State in this matter.

The remainder of the Monitor's first six months have been focused upon several major and interrelated issues which directly impact the Consent Decree's implementation, including:

- Lack of a budget for the State of Illinois resulting in uncertainties for beneficiaries of the Consent Decree and their families, agencies, staff, providers of all types of services, and advocates;
- Low wages creating a staffing crisis for providers of all types of services in their efforts to recruit and maintain adequate staffing and appropriate training for staff with existing inadequate funding for wages and high staff turnover levels;
- Initiation of waiver services still pending for more than one year, and for as much as three or more years, for 153 class members who have been selected between March, 2012 and March, 2014 via the PUNS process as well as for 101 Ligas ICFDD class members seeking DD Waiver services;
- Limited availability of small CILAs in certain geographic areas and for individuals with more intense medical, behavioral or physical needs;
- Inadequate availability of flexible, person-centered, integrated day activities or employment for individuals seeking such opportunities; and

- Reported potential for inadequate availability of resources for implementation of the Consent Decree during the second half of Fiscal Year 2016.

Despite the Defendants' ongoing commitment to compliance with the Decree, Mr. Records noted in his Third Annual Report that "resources for implementation, however, are significantly strained"<sup>2</sup> and that there were "several concerns identified, which, if not effectively addressed, could result in non-compliance".<sup>3</sup> The current Monitor's experience in Fiscal Year 2016 thus far is that the status of such resources has significantly worsened. In the current report, there is a finding of noncompliance in this area. (See section I herein.)

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<sup>2</sup> Third Annual Report of the Monitor, page 7

<sup>3</sup> Third Annual Report of the Monitor, page 2



## **OVERALL IMPLEMENTATION ACTIVITIES**

The Monitor has, over the past six months, engaged in innumerable activities consistent with the requirements of the Decree and as deemed necessary by the Monitor in order to become familiar with all aspects of the Ligas case. These include:

- Communicating regularly with the Parties and Intervenors;
- Reviewing data and other information provided by the Defendants at agreed upon intervals as well as on a more frequent basis whenever requested by the Monitor;
- Reviewing hundreds of documents provided by Class Counsel, Counsel for the Intervenors, service providers, Independent Service Coordination (ISC) agencies and advocacy organizations;
- Meetings with the management team and staff at the Division of Developmental Disabilities (DDD) and with the Department of Human Services (DHS) in Chicago and Springfield, including with the DDD Director and DHS Secretary;
- Participating in monthly conference calls with Plaintiffs' Counsel and Defendants regarding individual class member issues;
- Responding to scores of individual requests from Class members and their family members or advocates;
- Participating in meetings, conference calls and forums with ISC and provider agencies, provider organizations, family and advocacy groups, the Ligas Class Member/Family Advisory Council;
- Visiting Class members and those represented by Counsel for the Intervenors where they live, work and attend programs; and
- Addressing the impact of the State's fiscal crisis upon those protected by the Decree, including constant communication with the Counsel for Plaintiffs, Defendants and Intervenors as well as with service providers ranging in size and type from the largest agencies operating ICFs/DD and

CILAs to families receiving Home Based Services and individuals caring for one family member.

The Defendants continue to engage in actions required by the Consent Decree and Ligas Implementation Plan through such activities as:

- Continually exceeding, in number, the requirements to initiate services for class members both on the waiting list and living in ICFs/DD;
- Revising the process for developing Ligas Service Transitions Plans (LSTPs) as well as the format and required content of LSTPs;
- Continuing the PUNS Integrity Project to increase accuracy and validity of the PUNS selection process and updates;
- Reviewing the eighteen ISC agencies to monitor transitions from both the PUNS list and ICFs/DD to community-based services, although the survey protocol has recently been significantly reduced;
- Increasing the speed of responses to crisis situations; and
- Maintaining data required to assess compliance with the Consent Decree.
- Engaging in community outreach activities
- Participating in meetings of the Ligas Class Member/Family Advisory Committee
- Improving the processing of appeals

The 2013 Revision of the Implementation Plan required the establishment of the Ligas Class Member/ Family Advisory Committee.<sup>4</sup> This Committee meets quarterly at two locations that are connected by videoconferencing. DDD staff, Class counsel, the Monitor, family advocates and self-advocates attend these meetings. The Monitor has found these meetings to be informative and they have facilitated the Monitor's initial efforts to meet Class Members and family

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<sup>4</sup> Page 12

advocates. The Monitor will review reports and suggestions provided by this Committee with the Defendants and will respond to the Committee. Individual concerns and questions brought to the Monitor by Committee members will also be addressed promptly.

## **COMPLIANCE REQUIREMENTS AND ACTIVITIES**

Pursuant to ¶32 of the Consent Decree, Compliance Evaluation Standards were finalized in July 2012 to provide “objective standards to guide the Monitor in evaluating the Defendants’ compliance with the Decree.” The Ligas Implementation Plan, required by ¶29 of the Decree, is “supplemental to the Decree” and the Monitor therefore also reports on activities specified in the Implementation Plan as they relate to each of the Compliance Standards indicated below:

- I. Resources and Capacity
- II. Class Member List(s)
- III. Transition Service Plans
- IV. Transition for Class Members in ICFs/DD
- V. Crisis Services
- VI. Transition for Class Members on Waiting List
- VII. Outreach
- VIII. Implementation Plan
- IX. Data Reports

While each of these areas of compliance is addressed separately in the following sections of the current report, more information is provided related to the areas which currently have the greatest impact upon those protected by the Consent Decree.

**I. Resources and Capacity**

Paragraph 4 of the Consent Decree requires, in part:

Funding for services for each Individual with Developmental Disabilities will be based on the Individual's needs using federally approved objective criteria regardless of whether the Individual chooses to receive services in an ICF-DD or in a Community-Based Setting...

And Paragraph 5 of the Decree requires:

Annual budgets submitted by Defendants on behalf of their agencies shall request sufficient funds necessary to develop and maintain the services, supports and structures described in the Decree, consistent with the choices of Individuals with Developmental Disabilities, including Class Members. Defendants shall take steps sufficient to implement funding mechanisms that facilitate transition among service settings.

As there is no approved State budget for FY 2016, and it is not clear whether any proposals previously submitted on behalf of agencies early in the budget process are still under consideration, it cannot be assumed that the sufficient funds described in ¶5 will be available.

Section IV of the Ligas Implementation Plan (FY15 Revisions-6-5-15) addresses the development of community capacity, cites ¶4 and ¶5 of the Decree, and notes therein:

Within the first six years of the Consent Decree, the DDD will provide services to 3,000 individuals currently living at home with their families or in another community arrangement. These will include both Home-Based Support Services (HBS) and Community Integrated Living Arrangement (CILA) services, inclusive of all support services provided under the Waiver. In addition, an unidentified number of individuals will be moving from ICFs/DD to HBS or CILA services. This will require at least an estimated 20% expansion of Waiver capacity. (The exact amount cannot be known until the individuals in ICFs/DD are identified.) Individuals selected to receive services under this Consent Decree may choose from any qualified and willing providers as defined in

the Waiver. ... In order to meet the required expansion, current providers will be called upon to increase the size of their operations and new providers may be needed.<sup>5</sup>

Of significance is the fact that prior benchmarks for initiating services to these 3000 individuals have been met or exceeded. As of 12/1/2015, services have been initiated for 2,399 individuals, (96%) of the 2,500 individuals on the PUNS list required to be receiving services by 6/30/2016. This is reflective of the consistent, focused efforts being made by DDD, in cooperation with family members, service providers, ISCs and many others, to comply with the Consent Decree. However, the current Implementation Plan, also in Section IV, includes a subsection entitled "Facilitating Services for Selected Class Members." This subsection references Class members who were selected for Waiver services through the first four selections from the PUNS list but who had not begun receiving services as of September 1, 2014. The Monitor has worked closely for the past several months with DDD and the Plaintiffs to identify barriers confronting this group of class members and to strategize how best to meet their needs and expectations without further prolonging their time on the "pending services" list. This will likely be true, going forward, for ICF/DD Class Members who are awaiting moves into community-based settings if the "qualified and willing providers" noted above in the reference to Section IV of the Implementation Plan remain unable to expand their community development or even maintain current levels of services.

Based on the most recent data provided to the Monitor, as of December 14, 2015 a total of 101 Ligas ICFDD class members were noted to be awaiting requested

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<sup>5</sup> Ligas Implementation Plan (FY15 Revisions- 6/5/15), pages 14-15

services. Cases “pending” refers to Ligas ICFDD Class Members who have been seeking DD Waiver services for over one year. Major reasons for the pending status include:

Reason	Total
Waiting for downsizing or CILA development	36
Geographical preference	11
Individual/ guardian/ family want specific provider	10
Guardian not actively pursuing/waiting for appropriate CILA	8
Expanding search	5
Now moving forward in process	5
Undecided about receiving services	4
Behavioral needs	3
Geographic preference plus mobility needs	3
Individual deceased	3
Needs health stabilization	3
Communication between ISC and individual/guardian/family	2
Issue not identified	2
Age and Mobility needs	1
Behavioral needs plus communication between ISC and individual/guardian/family	1
Geographic preference plus mobility, behavioral and mental health needs	11
Geo preference plus medical and behavioral needs	1
Geo preference plus medical needs	1
Medical and physical needs	1
Stay in ICFDD	2
Visiting	1
Waiting for information from ICFDD	1

Data provided to the Monitor as of December 14, 2015 regarding Ligas Class Members selected from the Prioritization of Urgency of Need for Services (PUNS)

list indicates 153 cases are pending. Of these, 51 were selected in the 3 selection events or “PUNS pulls” in 2012 (February=7, June=8, October=36), 10 were selected in the September 2013 pull, and 92 in the March 2014 selection event.

Major reasons for the pending status include:

Reason	Explanation	Total
Geographical preference	Individual/guardian/family has a location preference; may be waiting for additional development or opening to occur.	22
Waiting on assessment	ISC is waiting for needed assessments to complete PAS Level II.	13
Undecided about receiving services	ISC is waiting for Individual/guardian/family to decide if they want to pursue offered DD Waiver services.	10
Expanding search	Individual/guardian/family has decided to expand their geographical preference.	9
Services refused- pending closure on PUNS	Individual/guardian/family chose to not participate in offered DD Waiver services and ISC needs to update PUNS.	9
Waiting for home to be ready	A provider has been identified and selected and development is underway. There is an agreement between individual/guardian/family and provider that they will be working together.	8
Issue not identified	More information is needed.	7
Communication between ISC and family	Individual/guardian/family is not always responsive, but ISC continues to make attempts at communication.	6
Family is now ready to move forward	Individual/guardian/family is now ready to actively pursue DD Medicaid Waiver services	6
Medicaid- family needs to follow through	Individual does not have active Medicaid. Individual/guardian/family needs to follow through on Medicaid application process.	6
Unable to locate	ISC has not been able to locate the individual and closed their PUNS case.	6
Undecided between CILA/AHBS	Individual wants DD Waiver services, but has not chosen between residential services or home supports.	6
Choosing Provider	Individual/guardian/family is in process of choosing CILA provider or interviewing Service Facilitators.	5
Individual/family want specific provider	Individual/guardian/family have a provider agency preference, may be waiting for additional development or opening to occur.	5
Behavior needs	ISC is having difficulty finding a provider that can meet the individual's behavioral support needs.	4
Geographic preference plus mobility needs	Individual/guardian/family has a location preference, and individual requires an accessible home.	4
Medicaid- financial eligibility issue	Individual had too many assets to be financially eligible for Medicaid.	4



Waiting for individual/family to respond to opportunities	ISC has presented referral/screening/service opportunities to the individual/guardian/family and is waiting for a response.	4
Ineligible Setting	Individual is not a Ligas Class member due to his/her residential setting.	3
Recent Medicaid approval	Individual has recently been approved for Medicaid.	3
Behavior and medical needs	ISC is having difficulty finding a provider that can meet the individual's behavioral and medical support needs.	2
Geographic preference plus behavior needs	ISC is having difficulty finding a provider within the preferred geographical location that can meet the individual's behavioral support needs.	2
Medicaid- denial	Medicaid application has been denied.	2
PAS Level II now complete	ISC has needed assessments and has now completed the PAS Level II.	2
Preferred home features	Individual/guardian/family is looking for a home that has their preferred design or setting.	2
Visiting	A provider has been identified and individual is participating in trial visits.	2
Geographic preference plus "multiple needs"	Individual/guardian/family has a location preference and multiple service needs	1
Geographic preference plus medical need	ISC is having difficulty finding a provider that can meet the individual's medical support needs within their desired location.	1
Guardianship issue	Guardianship is currently being established.	1
Medicaid- financial eligibility issue plus poor communication	Individual has too many assets to be financially eligible for Medicaid and individual/guardian/family is not responsive to ISC.	1
Medicaid- spend down issue	Individual lost Medicaid eligibility due to unmet spend down.	1
Mental health needs plus behavior	ISC is having difficulty finding a provider that can meet the individual's mental health and behavioral support needs.	1
Needs medical stabilization	Individual is currently experiencing health issues that requires stabilization before continuing in this process.	1
Out of state	Individual has moved out of Illinois.	1
Recent decision to pursue services	Individual/guardian/family who previously had refused services have recently decided they want to pursue offered DD Waiver services.	1
Waiting on assessment plus behavior	Individual's behavioral needs are making it difficult to successfully participate in evaluations that are required for PAS Level II assessment.	1
Want housemates with same religion/same gender	Guardian wants individual to live in a home housemates of the same religions and gender.	1

On 12/15/2015, the Monitor participated in a conference call of sixty-eight providers from across the state who provide ICFDD, CILA, ISC and Developmental

Training services (DT). Of that group, there was not one provider stating a willingness to consider expanding services while experiencing an unprecedented “staffing crisis” due to inadequate funding of wages, primarily for direct support personnel (DSPs) but also for supervisory and nursing personnel. Several agencies noted that despite the State’s and families’ interest in smaller settings, they are actually or at least considering increasing the size of residential settings in response to budget deficits caused by insufficient funding for program operations and lack of adequate staffing. ICFs/DD are also experiencing this workforce crisis, which is not surprising as neither CILAs nor ICF rates have increased since 2008 while operating costs have increased annually.

Without disclosing any names of individuals or agencies, following are a sampling of comments from service providers addressing their top concerns:

“In my 40+ years working in the disabilities field in Illinois, I have never encountered such a staff recruitment problem. I would characterize it as a desperate situation.”

“The most obvious risk is when you truly need two people present and on duty, but you may have only one staff member.”

“Providers are reporting double-digit vacancy and turnover rates; staffing programs at bare-minimum levels and focusing staff resources solely on the safety of individuals.”

“Without doubt, the number one issue affecting quality of life and the basic issues of safety and freedom from harm is the inability to recruit direct support staff because of the noncompetitive entry wage level.”

“All providers have stalled opening new CILAs and are also reducing existing CILA capacity to stay financially stable. Inability to attract and retain staff and uncertainty of future funding levels are the main factors that limit providers’ ability to open new CILAs. Across the board,

providers would be able to increase their capacity and open new homes, but they have no way of staffing them.”

“A four-person CILA which would serve three Ligas Class Members has been ready to open for four months but remains vacant because the agency cannot adequately staff existing operations.”

“20% of an agency’s population are Ligas Class Members. The agency has a 20% vacancy rate in direct support positions and is taking steps to move people into larger residential settings due to the inability to staff smaller settings. The agency has closed residential intake despite a long waiting list.”

“An agency is closing a CILA and moving residents to vacancies in other homes it operates due to staffing shortages.”

In addition, prior to, during and following that conference call, some problematic trends were identified which also point to inadequate funding:

- Three agencies reported having from 39 to 65 DSP positions vacant and are therefore not considering any referrals for residential expansion, including for Ligas Class Members living in an ICFDD who wish to move out.
- An agency with a turnover rate of over 30% among DSP positions faces significant challenges in staffing programs that serve people with significant medical and behavioral support needs because there is no differential within the CILA and DT rates to account for the necessary intensity of support.
- Chicago-based agencies are struggling to remain competitive with other employers in the area due to the city-wide minimum wage increase to \$10.00 per hour effective July 1, 2015, with no commensurate increase in reimbursement rates.
- The average (not starting) DSP’s wage is \$9.35 per hour which is insufficient to maintain staff. Even the providers who are able to pay \$1.00 to \$2.00 more per hour are experiencing significant vacancy and turnover levels.
- The State pays direct support workers in other programs significantly higher than the reimbursement wage for DSP personnel in community agencies, resulting in staff leaving community agencies to work for other State programs.

- One agency reported a \$500,000.00 annual loss in developmental training services due to the staffing ratio required for people including Ligas Class Members with intense behavioral and medical support needs.
- One agency is losing \$20,000.00 annually for each person living in an ICFDD setting due to significant medical needs, the need to pay a higher wage to attract staff and insufficient reimbursement rates. The provider cannot consider developing smaller CILAs for these individuals because the losses would increase.
- ISC agencies reported there is a growing list of families who have been selected for CILA services but cannot find a provider agency who will serve their family member due to their inability to expand services, the more intensive support needs of the person or the agency will only fill vacancies in existing settings which do not meet the families' expectations.
- Reliance on the 53R/D programs to address the needs of people with more significant medical and behavioral support needs is ineffective. This program assigns additional DSP hours to a specific person in response to a provider request based on the more challenging needs of the person. Often, the skill level that individuals require is beyond that of a DSP position and providers cannot fill existing DSP positions so having additional hours is not a solution.
- The FY 2016 reduction back to pre-September 1, 2014 levels in the Personal Needs Allowance overall and the significantly lower payment for people living in ICFs/DD severely limits individuals' ability to pay for needed items and to access community resources.
- ICFs/DD have had to cut existing services, including nursing and a variety of therapy services, to those currently being served due to inadequate rates.
- The Illinois Association of ICF/DD Providers, Inc. (IAIP) issued a report in April, 2015, reflecting a cost study of FY2013 which showed that 40% of the 204 ICF/DD facilities in Illinois at that time had a Negative Net Income in that year. Subsequently, it was reported that since that time losses have only increased as costs have risen and no reimbursement increases have been provided.
- In a special report regarding ICF/DD resources in August, 2014, Tony Records stated that, while not identifying Defendants' failure to increase rates as a violation of the Decree, "the overall level of rates for ICFs/DD and community based options have become increasingly problematic and pose an intermediate as well as long term insidious threat to continued compliance with the Decree. This issue must stay high on the agenda for the parties' attention, and will not go away on its own."

The Monitor fully appreciates the opportunity to bring individual concerns to key staff at DDD and has become accustomed to their immediate follow-ups in all cases. However, when the concern is inadequate staffing at a CILA or lack of community development due to the types of concerns noted above, even the best efforts of truly committed professionals cannot resolve the problems. The Monitor applauds the Defendants' success in meeting and exceeding previous benchmarks for both class members on the PUNS list and those living in ICFs/DD who want to move. However, the bleak picture painted by those previously most likely to implement the needed capacity building does not bode well for those already selected during PUNS pulls, but not yet receiving services or those still living in ICFs with hopes of moving to small CILAs in the community. Addressing the inadequacy of rates to provide acceptable wages for DSPs in both ICFs/DD and CILAs appears to be a good place to start.

While writing this report, the Monitor learned of ongoing efforts by a coalition of provider and advocacy organizations, among others, to get the attention of Defendants and legislators focused on the consequences of allowing this issue to remain unaddressed. The Monitor fully supports an increase in reimbursement rates to increase wages for DSPs in order to facilitate the provision of adequate, appropriate supports in both community living arrangements and ICFs/DD while encouraging the required expansion of community capacity, as noted in the Implementation Plan. Failure to remedy this crisis is already having a negative impact upon individuals, as noted above, and spreads to other areas of the Consent Decree as well. When committed providers are admitting that their staff

have to focus primarily on safety, it cannot be assumed that the entitlements of those protected by the Consent Decree are being guaranteed or that the expectations of the beneficiaries of the Decree and their families are being met. This, coupled with the absence of a State budget which prevents the Defendants from demonstrating compliance with ¶15 of the Consent Decree, creates unprecedented difficulties for all involved. Until such time as concrete steps are taken to enact a State budget and address the staffing crisis and resulting decrease in service quality as well as lack of development in the community, the Monitor finds noncompliance with this compliance standard.

The Defendants’ activities related to the budget have typically been described in this section of Annual Reports of the Monitor. However, in the absence of a State budget, no meaningful information is available at the current time related to budget proposals, appropriations, spending plans or anticipated individual allocations.

It is worthy of note, however, that the Ligas Implementation Team remains intact with all eighteen positions filled despite turnover of specific staff in some of the positions:

Compliance Coordinator	1 position
Program and Data Support Staff	1 position
Bureau of Quality Management Staff	7 positions
Bureau of Transition Services Staff	4 positions
Appeals Unit Staff	1 position
Rates Section Staff	1 position
Medicaid Waiver Staff	3 positions

The Third Annual Report recommended that three leadership positions be added within DDD to provide additional support in the areas of employment, waiver services and service coordination. Although such specific positions were not created, there are now key staff whose responsibilities clearly include the Employment First initiative, the expanded home and community-based services waiver and oversight of the eighteen service coordination agencies. The Monitor agrees that a Director's position in each of these areas is preferable, but applauds DDD's staff reassignments, particularly during the current fiscal climate, which do not diminish the Ligas Management Team numbers while addressing these significant areas related to the Decree's implementation.

Unfortunately, the Ligas Family Advocacy Program, which had been reported in the Third Annual Report be "fully operational and staffed" and about which the previous Monitor had been receiving very positive feedback from families of Class Members, is now only partially staffed. It is unclear whether additional funding will be provided once there is a state budget in place. It is recommended that funding be reinstated to support this valuable resource for Waiting List Class members and their families statewide. Similarly, the temporary increase, as referenced above, in the monthly Personal Needs allowance for Class Members living in ICFs/DD and CILAs during FY2015 should be reinstated.

## II. Class Member List(s)

Paragraphs 8 and 9 of the Consent Decree require that the defendants maintain a statewide database in which all Class Members are enrolled and which, along with waiting list data, is promptly revised. The Implementation Plan requires that DDD review the adequacy of the PUNS database.

Paragraph 2 of the Consent Decree requires that there is a list of Class Members who qualify for Medicaid Waiver services, live in an ICF/DD with nine or more residents and have affirmatively requested community-based services or placement in a community-based setting. Another list is required of Class Members who qualify for Medicaid Waiver services, live in a family home and are in need of and have affirmatively requested home and community-based services or services in a community-based setting. The individuals on this list are known as Waiting List Class Members and this list is considered a subset of the PUNS list.

According to the Third Annual Report, and despite previous inconsistencies as well as outdated information in the Class Member lists, DDD has begun addressing the problems, including establishing an automated process to add new Class Members to the PUNS list as well as remove those who are no longer eligible. Data regarding overdue PUNS updates are reported to the parties and the Monitor quarterly, most recently on 9/1/2015, and show progress in decreasing the number of overdue updates.



The first three annual reports have identified the need for a comprehensive integrated data system within DDD and DHS. Over the next few months, the Monitor will review with DDD and DHS the status of this issue.

### III. Transition Service Plans

The Third Annual Report of the Monitor as well as the 2015 Revisions of the Implementation Plan provide comprehensive reviews of the progress that has taken place over the past two years in addressing significant problems within the transition planning process. That level of detail will not be repeated herein. Rather, a summary of improvements and of next steps is being provided.

The Consent Decree is quite specific with regard to who participates in the development of Transition Service Plans (TSPs), what is included therein, under what circumstances they are required, and that they are not to be “limited by the current availability of services but be within the confines of the waiver and the State Plan”.<sup>6</sup> The Third Annual Report notes progress toward “the development and operationalizing of a Transition Service Plan” and acknowledges that “Converting a system from virtually no transition service planning to a person-centered approach as required in the Decree necessitates a carefully planned and deliberate process that will continue to take time to evolve.”<sup>7</sup> This evolution has included a consultant’s work to make needed modifications and provide training as well as technical assistance; a comprehensive review of 114 TSPs, which found inadequate participation of class members in their own transition planning, employment opportunities not being considered or offered; difficulty experienced by class members with significant behavioral or medical needs in finding providers willing or able to provide these services; inadequate use of TSPs as the foundation for the development of the Individual Support Plan (ISP) following placement;

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<sup>6</sup> ¶14, Ligas Consent Decree, page 10

<sup>7</sup> Third Annual Report of the Monitor, 9/30/2014, page 22

limited choices of activities and services in certain regions of the state. One year later, review of new TSPs reportedly showed marked improvement. The TSP form and instructions were then modified; class members were trained in effective participation in the transition planning process; and training continued for ISC agencies, focusing on those whose transition plans indicated least progress.

Over the next six months, the Monitor will select a sample of the transition plans completed since January 2015, at which time the most recent version of the plans was consistently in use. The Monitor's Data and Program Analyst, Melanie Reeves Miller, will assist in reviewing and evaluating these plans to determine whether further revisions or training are needed and whether the plans are facilitating provision of appropriate services and supports chosen by the class members, families or guardians with whom the plans were developed. In addition, concerns raised by the Monitor in the Third Annual Report will be considered, including whether preferred size of CILAs, real employment and day services are being provided as described in the TSPs.

Related to this standard, in October, 2015, DDD developed and sent out questionnaires to 201 of the 700 individuals selected in March of 2014 for CILA services or Adult Home Based Services (AHBS), but chose AHBS. Questions included whether or not families were satisfied with the selection process, why a particular service was selected, whether they had visited CILAs, how satisfied they were (are) with their ISC agency. A remarkable number of responses, 89 or over 40%, was received within approximately one month and a staff person at DDD has

been designated to review the responses and follow up with those who included questions or concerns. The Monitor has requested and received copies of the 89 responses and will confer with DDD on the outcome of this process, including perhaps contacting some of the respondents independently.

#### **IV. Transition for Class Members in ICFs/DD**

The Consent Decree requires in ¶17 that within six years after the approval of the Decree, all class members residing in ICFs/DD as of the date of the approval of the Decree will transition to community services or community-based settings consistent with their transition plans if, at the time of the transition, the class member requests placement in a Community-Based Setting as confirmed and documented in accordance with the Decree.

It is required that one-third of the class members in this category transition to the community by 12/15/2013, two-thirds by 12/15/2015, and all by 6/15/2017. The actual target numbers are fluid, based upon ongoing additions and removals from the list defining this category, but for the 2013 and 2015 target dates the Defendants exceeded the target numbers. As of 12/31/2015, the target number of class members residing in ICFs/DD to be transferred to the community was 932 of the 1399 class members known in this category as of 6/15/15. The actual number of such transitions as of 12/1/15 was 1255 of 1446 then active Ligas ICF/DD class members, more than 300 beyond the target.

Defendants are to be congratulated on their efforts to streamline the process for these transitions and on the fact that the overwhelming majority (1235, 98%) of these class members who have transitioned have received funding for CILAs, as they requested. The remaining individuals requested and received Home Based Funding (17) and funding for Community Living Facilities (CLFs) (3).

An issue that will be pursued with DDD by the Monitor, however, is the fact that 63% of these transitions into CILAs as of 12/1/2015 were into CILAs serving 8 individuals, 19% into CILAs serving 4 people, 9% into CILAs serving 6 people, 5% into CILAs serving 5 people, 2% into CILAs serving 7 people, 1% into CILAs serving 3 people, 1% into CILAs serving 1 person and none into CILAs serving 2 people.

In addition, and as was suggested in the Third Annual Report, while ICFs/DD downsizing or closures continue, class members must be offered a variety of options and opportunities to make informed decisions about where, how and with whom they choose to receive services and supports. The Monitor will continue to work closely with the defendants in tracking how such choices are facilitated, particularly in light of the obstacles related to community development that are noted in Section I herein.

Finally, the Monitor will continue to work with DDD and the Plaintiffs to facilitate transitions of Ligas ICF/DD Class Members from the “pending services” list.

**V. Crisis Services**

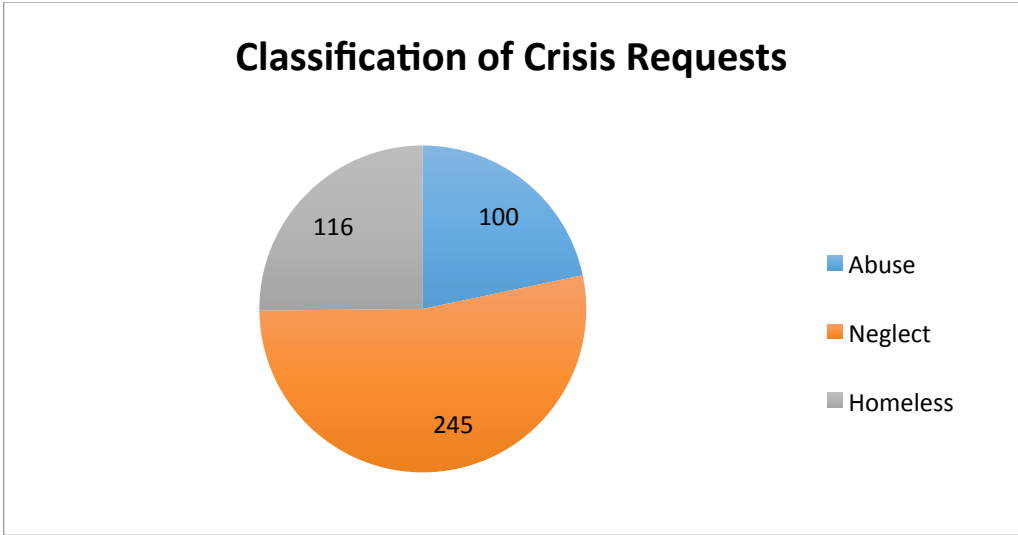
As indicated in ¶21(a)-(b) of the Ligas Consent Decree, “an individual is in a situation of “Crisis” if he or she is at imminent risk of abuse, neglect, or homelessness. The provision of interim emergency services (including interim placement in an ICF-DD where no placement in a Community-Based Setting 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. A review of crisis requests from July 1, 2014 through June 30, 2015 indicated that 485 crisis service requests were received and reviewed by DDD with 461 requests approved.<sup>8</sup>

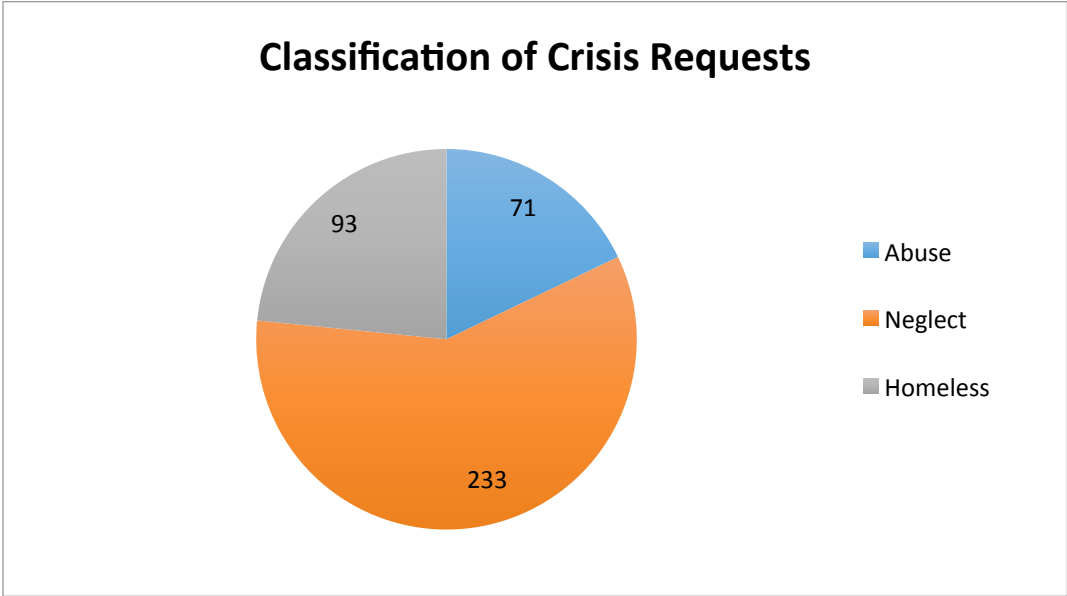
According to the crisis data, between 7/1/14 and 6/30/15, one hundred (100) crisis requests received were classified as abuse, 245 were classified as neglect, and 116 were due to the individual being homeless.

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<sup>8</sup> Ligas Data Report June 30, 2015



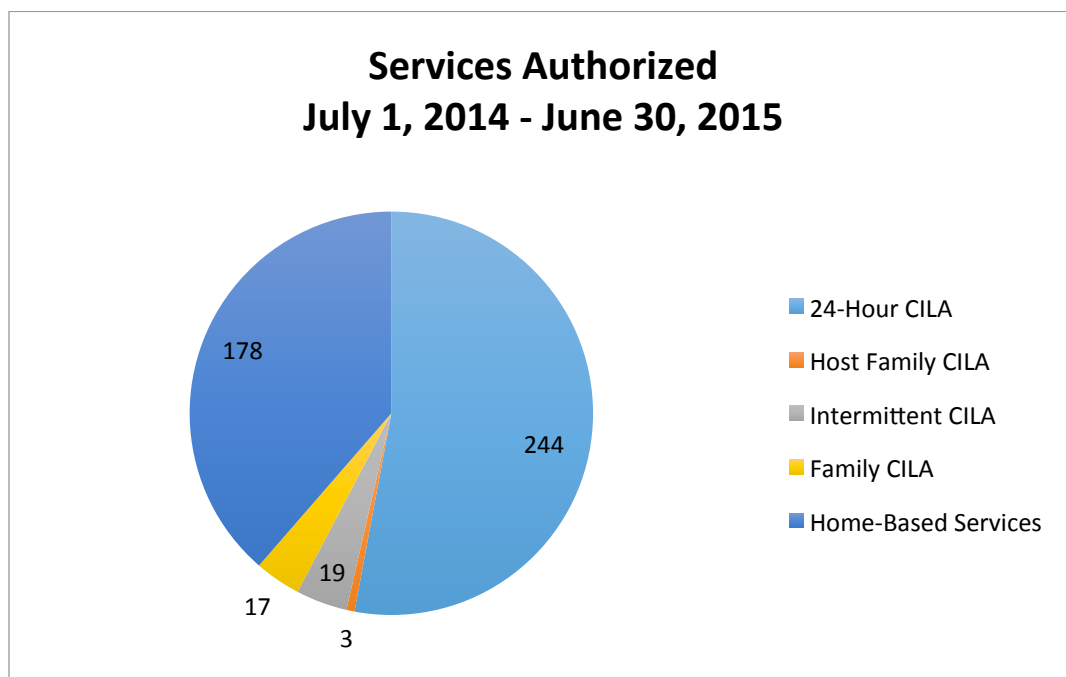
The above data indicates a slight increase from data ending 6/30/14 (as referenced in the chart below).



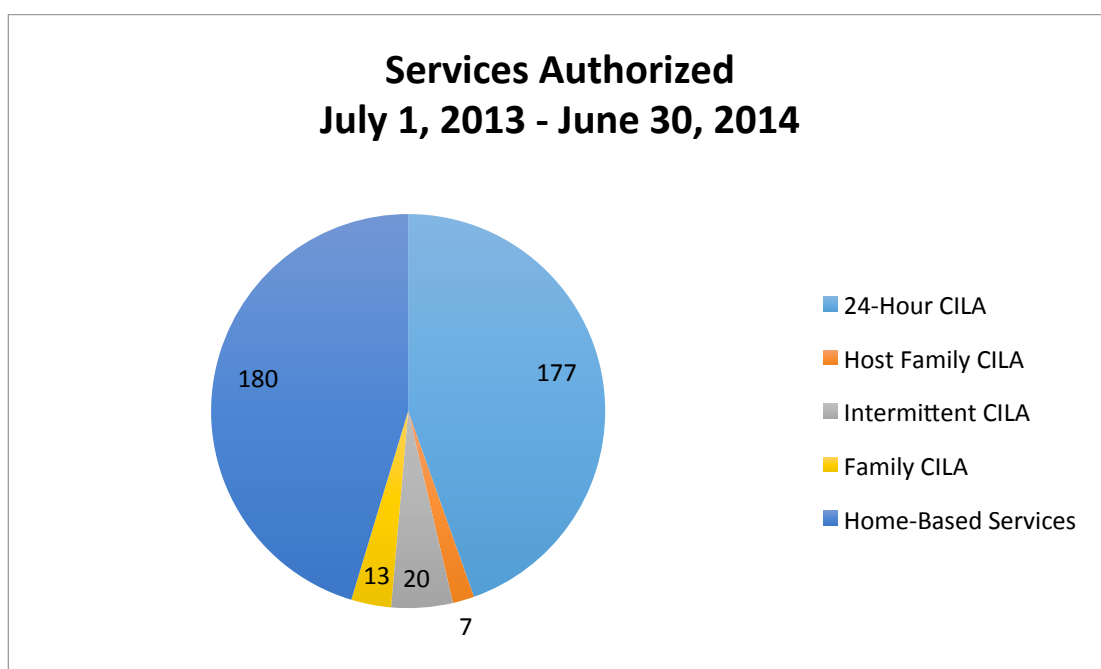
Services provided to class members in crisis included four types of CILA (Community Integrated Living Arrangement) options: 24-Hour CILA, Host Family CILA, Intermittent CILA, and Family CILA, in addition to Home-Based Support Services (HBS). Of the 461 crisis requests approved, 244 were approved to receive



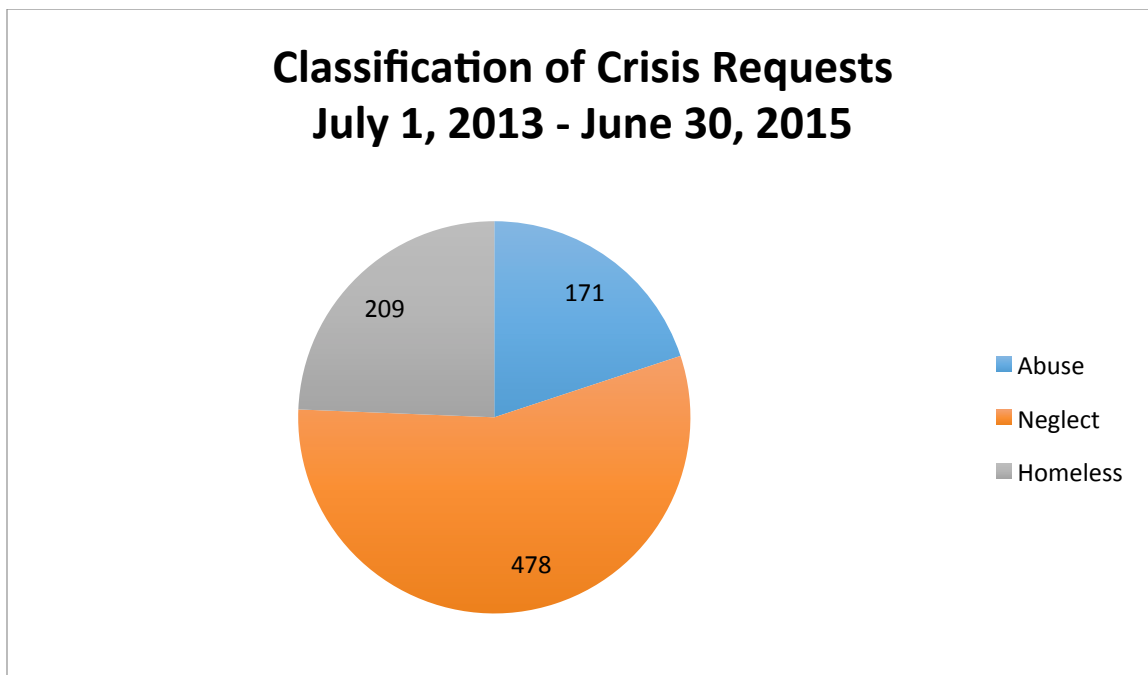
24-Hour CILA, 3 were approved to receive Host Family CILA, 19 were approved to receive Intermittent CILA, and 17 were approved to receive Family CILA. Home-Based Support Services were approved for 178 class members:



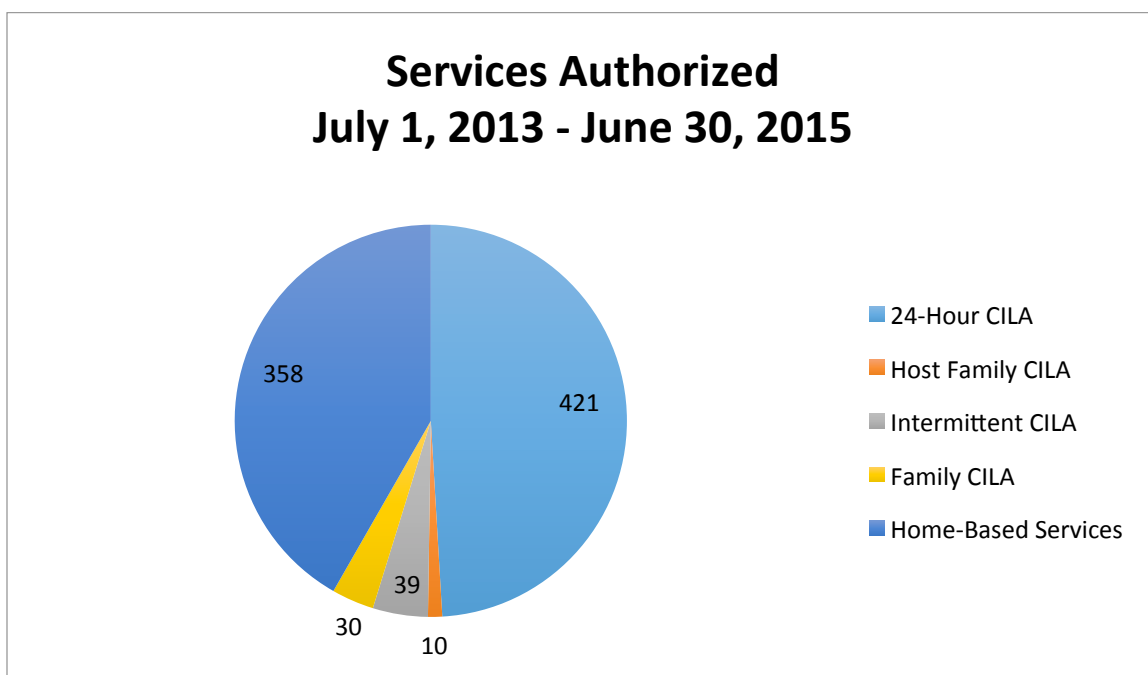
Compared to data ending 6/30/14:



Combining the two reporting years (7/1/13-6/30/15), a total of 858 crisis requests have been approved by DDD.



Services were provided to class members in crisis within four types of CILA (Community Integrated Living Arrangement) options:



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. The Monitor noted, during the 2014/2015 reporting period, a marked improvement in timely review of the crisis packet upon receipt by defendants. Additionally, review of the data associated with the 461 crisis requests received between July 1, 2014 and June 30, 2015 revealed that, in nearly all cases, a “safety plan” had been determined to be in place for the class member in order to ensure safety and reduction of risk while awaiting approval of services. However, the Monitor has concerns as to the determination of adequacy of a safety plan wherein the class member in crisis is not in a permanent or stable situation (e.g., jail, psychiatric hospital, nursing home). It is recommended that the Defendants and Monitor confer to clarify criteria for determining adequacy of a safety plan.

For the most part, State Defendants had ensured prompt authorization of services following review of a crisis packet. However, the Monitor noted many cases where, although a safety plan was indicated as being in place, the initiation of services was delayed for more than a week and sometimes for up to a month or more. Based on the current data reviewed, for 93 individuals (20% of the 461 individuals), services did not begin for at least ten days with some delays in excess of a month.

Finally, review of crisis data for the two-year reporting period indicated that eight (8) class members had requested crisis services on two occasions. In all of these cases, the safety plan/service put into place following the initial crisis situation proved unsuccessful after a period of between one and nine months, at which point the class member was again found to be in crisis and in need of services. Without further data and information, it appears that the most recent authorizations of services in response to the second crisis situations have been adequate.

As recommended in the Monitor's third report, "The DDD, in conjunction with the Monitor and input from the Parties, will conduct an analysis of crisis data to determine the relationship between crisis applicants and the PUNS list. This analysis will be completed by September 30, 2015." The DDD conducted the above referenced analysis and provided to the Monitor on January 5, 2016. According to the analysis, DDD utilized FY13 and FY14 data for a two-year comparison.

FY13 and FY14 Approved Crisis Placements	
PUNS Category prior to Crisis Date	Total
CRITICAL	206
EMERGENCY	352
FULLY SERVED	28
MOVED	1
OTH CLOSED	21
PLANNING	19
WITHDRAWN	4
NOT ON PUNS PRIOR TO CRISIS	14
<b>Total</b>	<b>645</b>

FY13 and FY14 Approved Crisis Placements and Length of time on PUNS Waiting List		
Time Period	Number of Placements	% of Total
One Month or Less	43	7%
Over 1 Month to 1 Year	147	23%
1 to 2 Years	85	13%
2 to 3 Years	52	8%
3 Years or More	318	49%
<b>Total</b>	<b>645</b>	<b>100%</b>

The above charts show the PUNS enrollment categories for the crisis requests, as well as the length of time of PUNS enrollment prior to receipt of the crisis request. It should be noted that each individual seeking community-based services, including those in crisis situations, must enroll in PUNS. Therefore, some enrollments were completed as the crisis requests were being processed.

The previous Monitor's basis for recommending this analysis was to determine whether local PUNS outreach activities were identifying individuals in need or whether individuals were coming forward for crisis services who were largely unknown to the system. According to DDD, its analysis showed that the majority of individuals were previously identified and enrolled on the waiting list, thus not reflecting outreach to be a major concern.

The DDD did, however, identify that some individuals in crisis situations were not selected for services because their enrollments were out of date and did not reflect their current circumstances. The PUNS Integrity Project has been implemented to bring and maintain PUNS enrollments current with the intent to address this concern.

While the Defendants noted the above as reasons for individuals in crisis situations not being selected for services, the Monitor is concerned that nearly half (49%) of the individuals with approved crisis placements were on the PUNS waiting list for 3 years or more.

The Monitor greatly appreciates the assistance of Melanie Reeves Miller, the Monitor's Data and Program Analyst, in conducting this review of Crisis Services.

## **VI. Transition for Class Members on Waiting List**

The Consent Decree requires that Class Members described in ¶2 of the Decree will transition to the community and be referred to as Waiting List Class Members.<sup>9</sup> A specific schedule for such transitions to community-based services or community-based settings is delineated in ¶23 which requires the following:

- 1000 by June 15, 2013
- Additional 500 by June 15, 2014
- Additional 500 by June 15, 2015
- Additional 500 by June 15, 2016
- Additional 500 by June 15, 2017

Following June 15, 2017, Waiting List Class Members will receive community-based services or placement in a community-based setting at a reasonable pace.<sup>10</sup>

The Implementation Plan<sup>11</sup> incorporates criteria for the prioritization of selections of Waiting List Class Members, including:

- Recorded on the PUNS (Prioritization of Urgency of Need for Services) database as being in an emergency situation and needing out-of-home supports or in a critical situation and needing in-home or day supports;
- Residing at home with a primary caregiver age 75 or over;
- Leaving the Public School System in the past 5 years; or
- Residing at home with a primary caregiver age 60 or over.

Within each category, selections will be made by the length of time on the database.

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<sup>9</sup> ¶22(c)

<sup>10</sup> ¶23

<sup>11</sup> Implementation Plan, 2015 Revisions, 6/5/2015, section VII, page 26-27

As stated previously herein, benchmarks for 2013, 2014 and 2015 have been reached or exceeded and defendants have already reached approximately 96% of the June, 2016 target of 2500 such placements. This is a tremendous achievement and demonstrates the State's commitment of necessary resources as were needed. However, as noted in Section I herein, the service delivery system is currently facing exceptional barriers to ongoing success and the Monitor will continue working with the Parties, providers, advocates and families to resolve systemic problems endangering the ongoing placements of Ligas Waiting List Class Members.

In addition, the Monitor will confer with the DDD to clarify the situation of those on the "pending services" list who have been selected via the PUNS process but for whom services have not yet been initiated, in light of the stated priority for PUNS selections to be made within each category on the basis of length of time on the database. It appears that this criterion could perhaps be applied to those waiting on the "pending services" list as well.

Finally, the requirement to place remaining Waiting List Class Members "at a reasonable pace" following June 15, 2017 requires that the Parties, with all due speed and with input from the Monitor, direct their attention to defining "reasonable pace" and planning its implementation.

## **VII. Outreach**

The Consent Decree at ¶25 states:

Defendants shall maintain a fair and accessible process by which Individuals with Developmental Disabilities or their legal guardians can affirmatively request in writing to receive Community-Based Services and/or placement in a Community-Based Setting or to receive ICF-MR services in an ICF-DD, and Defendants shall maintain up-to-date records of those requests.

Defendants' outreach efforts are well documented in both the Third Annual Report of the Monitor and the 2015 Revisions of the Implementation Plan. These details will not be repeated herein. However, a summary of some of the recent and ongoing efforts follows:

### **Community Outreach**

- ISC agencies are trained on the requirements of the Consent Decree and the provisions of the Implementation Plan.
- DDD, the Plaintiffs and the Monitor participate in information sessions about the Consent Decree for self-advocates, families, providers and others.
- DDD maintains a user friendly ISC locator on its website.
- The DDD website includes an overview of the Consent Decree as well as the Decree itself, Annual Reports of the Monitor, information about Class Members' rights and eligibility.
- DDD has established, publicized and maintains a Ligas complaint contact within the Division who maintains a log of complaints and related follow-up activities.

### **Outreach to Persons in ICFs/DD**

- Most recently, DDD secured the services of an independent contractor, The Council on Quality and Leadership (CQL) to identify potential Class Members living in ICFs/DD. These potential Class Members do not include those who specifically excluded themselves from the Class by having objected to the Decree prior to its approval



or by submitting a written request to be excluded prior to the compilation of the initial class list. CQL's work will continue through January 31, 2016 and a final report will then be issued. The chart below details CQL's process during FY 14 and FY 15.

	<b>Outreach Activity</b>	<b>FY15</b>	<b>FY16</b>
1	Total Potential Class Members Pending Contact	2620	590
2	# With Initial Phone Contact	546	1272
3	# Choosing Not to Meet w/Outreach Contractor	393	941
4	# Choosing Not to Meet at This Time, but Want Future Contact	29	32
5	# Choosing to Meet w/Outreach Contractor	124	299
5a	# Completed Written Request for Community Services Through Outreach	32	83
5b	# Undecided	18	36
5c	# Pending	13	46
5d	# Choosing ICF/DD	61	134

### **VIII. Implementation Plan**

Paragraph 28 of the Consent Decree requires that the Implementation Plan be updated and amended at least annually. The Defendants have complied with this requirement and the most recent revisions were completed in June, 2015.

The Implementation Plan updates and proposed revisions are provided by the Defendants to the Plaintiffs, Intervenor and Monitor for consideration. Each year, negotiations have taken place and resulted in jointly developed revisions being agreed upon before being submitted to the Court. At each scheduled Parties' meeting, the Defendants provide a verbal update of the Plan's activities and respond to inquiries from Class counsel, counsel for the Intervenor and the Monitor.

It is recommended that the next proposed revisions be presented at the Parties' meeting which follows the one already scheduled for January 21, 2016.

**IX. Data Reports**

Paragraph 33 of the Consent Decree requires the Defendants to provide to the Monitor, Class counsel, Intervenors and Intervenors' Counsel and publicly make available, a detailed report containing data and information sufficient to evaluate Defendants' compliance with the Decree and Defendants' progress toward achieving compliance. Defendants are required to provide these data reports not less than every six months.

The Monitor acknowledges that the Ligas Data Reports are submitted timely and that interim data requested by the Monitor is also provided promptly. DDD staff are consistently available to answer the Monitor's questions and address concerns related to data reports.

## **Closing Comments**

Having been appointed by the Court only six months prior to completing this report, the Monitor is grateful to Mr. Records for doing all of the critical foundational work at the initiation of this case and for all that he accomplished over the following four years. Appreciation is also extended to the Parties, Intervenors, families, advocates, providers and Class Members who have shared their expertise and insight into all aspects of this case as well as demonstrating what can be achieved through strong, cooperative efforts. The Monitor looks forward to continuing to work toward shared goals for the benefit of those protected by the Ligas Consent Decree.

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