

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

## **Fifth Annual Report of the Monitor**

January 20, 2017

### **INTRODUCTION**

This report is respectfully submitted to the Court, the Parties and the Intervenors in accordance with ¶34 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 shall be made publicly available. Such reports shall include the information necessary, in the Monitor’s professional judgement, for the Court, Plaintiffs and Intervenors to evaluate Defendants’ compliance or non-compliance with the terms of the Decree.”

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. 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 schedule was changed to January, 2016 to allow the Monitor six months for an initial evaluation of the Defendants’ compliance with the terms of the Decree. The Fourth Annual Report was filed with the Court and distributed to the Parties and Intervenors on January 7, 2016. It was subsequently made available on the DHS website and distributed widely.

The ongoing cooperation of the Defendants, Plaintiffs' counsel and representatives, counsel for the Intervenors, service providers, advocacy organizations, family associations and others too numerous to mention has been invaluable in completing the current report. Input from those protected by the Decree and their families remains critical to the Monitor's efforts on an almost daily basis as well as during annual evaluations of the Decree's effectiveness at each stage of its implementation.

## CHALLENGES

The Monitor's Fourth Annual Report cites the lack of a State budget for Fiscal Year (FY) 2016 in Illinois and describes in detail how funding was guaranteed for providers serving all of those protected by the Consent Decree. It is stated therein that the lack of a budget for the State of Illinois resulted in uncertainties for beneficiaries of the Consent Decree and their families, agencies, advocates, staff and providers of all types of services. Federal Court orders to address these issues are quoted therein and the Monitor's requirement of monthly updates from DHS regarding timeliness of such payments is referenced. This "Information Request Regarding Ligas Payments" remains in effect. In light of the lack of a State budget for FY17, which continues to date, the Plaintiffs, Defendants and Intervenors prepared an "Agreed Order to Maintain Compliance with Consent Decree" and filed with the Court on 6/26/16 a Joint Motion to Approve Agreed Order. This Order, which was approved by United States District Judge Sharon Johnson Coleman on 6/27/16 and entered on 6/28/16 requires, in part, that:

"The Comptroller shall continue to timely approve and make payments for all services, programs and personnel, at a level and within the time period that such payments were made in Fiscal Year 2016, that are necessary to comply with the Consent Decree and Implementation Plans. The Courts previous orders of June 30, 2015 (Dkt. #597), August 18, 2015 (Dkt.#610) and September 1, 2015 (Dkt. #624) are incorporated herein and shall continue in effect. This Order shall remain in effect until the earlier of the effective date of the Fiscal Year 2017 budget or July 1, 2017, or until further order of this Court."

“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 on a monthly basis to enable her to evaluate and to advise the Court and the Parties regarding the State’s compliance with the Consent Decree and Orders entered by this Court.”

“If at any time the State believes that it may not be able to comply with any provision of the Consent Decree or this 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 State shall maintain its expedited payments consistent with the terms and conditions that existed during FY 2015.”

To date, Defendants have maintained funding at the same level paid in FY 2016 which, though noted to be inadequate in the Fourth Annual Report, remains in compliance with the 6/28/16 Court Order.

The Monitor’s Fourth Annual Report addresses the fact that low wages, particularly those paid to Direct Support Professionals (DSPs), resulted in a staffing crisis for providers of services in their efforts to recruit, train and maintain adequate staffing with the existing wages. There has been a great deal of discussion at all levels during the past year without improvement in this situation. The staffing crisis continues as another year has passed with no relief in terms of salary increases, DSP vacancy rates either staying the same or increasing and the

heightening impact of no increases in rates to providers since 2008 combined with ongoing higher costs of operating.

The Monitor's Fourth Annual Report describes delays in initiation of waiver services for class members once they have been selected from the PUNS list. Herein it is noted that a new tracking system has been developed to actively monitor those class members seeking services.

The Monitor's Fourth Annual Report notes limited availability of small CILAs in some geographic areas as well as for individuals with more intense medical, behavioral or physical needs. The Monitor has been informed during Fiscal Year 17 that this situation is worsening as new CILA development is being delayed due to lack of availability of DSPs willing to accept current wages and that some existing small CILAs are at risk of either closing or being consolidated into larger homes due to staff turnover rates of up to 70%. Some providers are actually stating that they are no longer able to accept into their CILAs individuals with more significant needs due to the provider agencies' inability to recruit, repeatedly retrain (at significant cost) and consistently maintain sufficiently skilled staff to serve these individuals.

The Monitor's Fourth Annual Report discusses inadequate availability of flexible, person-centered, integrated day activities or employment for individuals seeking such opportunities, all of which remains problematic. Efforts have begun through the Employment First initiative that appear to be promising but it is too soon to

evaluate the outcomes. In addition the day training requirement for those living in CILAs is a deterrent to those individuals looking for homes in the community but preferring other daytime activities that are more customized and/or integrated into the community.

The Monitor's Fourth Annual Report notes that despite the Defendants' ongoing commitment to compliance with the Consent Decree, the previous Monitor had expressed concern that resources for implementation are "significantly strained" and that "if not effectively addressed could result in non-compliance". The current Monitor's finding, in January, 2016, of non-compliance with regard to Resources and Capacity is repeated herein. (See section I below.)

The Monitor has initiated conversations with the Division of Developmental Disabilities (DDD) within the Department of Human Services (DHS) regarding the processes utilized to monitor the quality of services provided to beneficiaries of the Consent Decree. Information requests were submitted to DDD and all documents were promptly provided. Discussions are ongoing among the Monitor and the Parties. (See section I. Resources and Capacity)

## OVERALL IMPLEMENTATION ACTIVITIES

The Monitor has, over the past year, sought and also received unsolicited input regarding many aspects of the implementation of the Ligas Consent Decree. Such activities are consistent with the Decree's Compliance Evaluation Standards which state, in part:

“On an ongoing basis, the Monitor will seek and encourage class members, families and guardians of class members, the private provider community and members of the general public to provide written and verbal feedback on issues related to compliance with the Decree. Informal meetings and conference calls will also be conducted with defendants' counsel and staff, class counsel and intervenors' counsel regarding their respective experiences as well as information they may have with regard to compliance activities.”

The Monitor's implementation activities over the past year included:

- Communicating regularly with the Defendants, Plaintiffs and Intervenors;
- Convening more frequent Parties' meetings than had previously been the practice in order to address the most critical issues impacting those protected by the Consent Decree as well as to attempt to reach consensus on the development of the Ligas Implementation Plan 2016 Revisions;
- Convening meetings to address the “Reasonable Pace” provision of the Consent Decree which is scheduled to become effective on June 15, 2017;
- Reviewing data and other information provided by the Defendants at agreed upon intervals as well as on a more frequent basis as requested by the Monitor;

- Reviewing hundreds of documents provided by Class Counsel, Counsel for the Intervenors, service providers, Independent Support Coordination (ISC) agencies, advocacy organizations and individuals;
- Participating in Status Conferences, which are currently being held approximately every 60 days, with Judge Coleman, Defendants, Class Counsel and Counsel for the Intervenors;
- Meeting with members of the management team and staff at the Division of Development Disabilities (DDD) within the Department of Human Services (DHS);
- Participating in monthly conference calls with Plaintiffs' Counsel and Defendants regarding individual class member issues;
- Responding promptly to frequent inquiries from class members and their families, guardians and advocates;
- Presenting information regarding Ligas matters to large and small groups of parents, ISCs, service providers, provider organizations, advocates, the Ligas Class Member/ Family Advisory Council, and the Ligas Family Advocacy Program;
- Participating in a panel convened by the Senate Committee on Human Services to address the status and future of the implementation of the Ligas Consent Decree;
- Visiting individuals where they live, work and attend programs;
- Initiating numerous conference calls with Defendants, Plaintiffs and Intervenors to address significant issues on a timely basis;
- Initiating a discussion with the Developmental Disabilities Division (DDD) of the Department of Human Services (DHS) regarding the overall quality monitoring of Independent Support Coordination (ISC) agencies and Community Integrated Living Arrangements (CILAs); and
- Addressing, in a variety of ways, the impact upon those protected by the Consent Decree of the State's overall fiscal crisis and the specific issue of inadequate wages for Direct Support Professionals.



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

- Meeting or numerically exceeding the Consent Decree's benchmarks for initiating services for class members on the waiting list as well as those living in ICFs/DD;
- Responding promptly and comprehensively to information requests from the Monitor;
- Participating in issue specific conference calls and videoconferences initiated by the Monitor beyond those which are scheduled on a routine basis;
- Participating in monthly conference calls with the Monitor and Equip for Equality (EFE) regarding individual Class member issues as well as promptly following up on individual Class member issues brought directly to DDD by the Monitor in response to contacts from family members and guardians;
- Conducting reviews of all of the ISC agencies and a sample of the CILAs on an annual basis as well as responding to the Monitor's requests for additional information regarding the processes and protocols involved in this system;
- Maintaining agreed upon data required to assess compliance with the Consent Decree;
- Participating in a cooperative, though eventually unsuccessful, effort with the Plaintiffs, Intervenor and Monitor to reach consensus on the content of the 2016 Revisions of the Ligas Implementation in order to continue the practice of filing jointly with the Court the 2016 Revisions of the Ligas Implementation Plan;
- Recently developing, with input from the Plaintiffs and Monitor, a more comprehensive list of those who have been selected to receive services from the Prioritization of Urgency of Need for Services (PUNS) database and are still seeking services; and
- Organizing and participating in quarterly meetings of the Ligas Class Member/Family Advisory Committee.

The Ligas Class Member/ Family Advisory Committee was established in compliance with the 2013 Revision of the Ligas Implementation Plan and meets quarterly at two locations which are connected by videoconferencing and telephone. DDD staff, Class counsel, the Monitor, family advocates and self-advocates regularly attend these meetings and guest speakers are invited to meetings upon request of the members or as suggested by DDD or the Monitor. The Monitor finds these meetings to be informative and brings questions, concerns as well as suggestions from these meetings to others as necessary.

## **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, as required by ¶29 of the Decree, “is supplemental to the Consent Decree and the Monitor therefore also reports on activities specified in the Implementation Plan as they relate to each of the following Compliance Evaluation Standards:

- 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

As noted in the Fourth Annual Report of the Monitor, while each of these areas of compliance is addressed separately in the following sections of the current report, more attention is given 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:

“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...”

“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...”

Paragraph 5 of the Decree requires, in part:

“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.”

In addition, the Compliance Evaluation Standards indicate that:

“The defendants will provide the proposed annual budget and cost assumptions to the parties, intervenor and Monitor that specify spending plans for all activities related to compliance with the Decree in sufficient detail to permit an evaluation of Defendants’ compliance with the Decree.”

For Fiscal Year 2017, the second consecutive year, there is no approved State Budget and no assurance that this impasse will be resolved within the second half of Fiscal Year 2017. The Implementation Plan 2016 Revisions document recognizes that Federal Court orders continue to require that all payments be made for “all services, programs and personnel for all beneficiaries of the Consent Decree, 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”. While the Defendants continue to comply with the Orders, including providing to the Monitor monthly reports of payments made, DHS has not provided to the Monitor, Plaintiffs or Intervenors, or within the 2016 Implementation Plan Revisions, any indication of how the agency will be addressing the shortage of DSPs due to inadequate wages.

The DHS website includes the 2/17/2016 Illinois Budget Briefing Presentation which states that “The proposed budget for FY 17 continues to provide critical services to the most vulnerable in Illinois. The Agency continues its commitment to rebalancing—moving individuals with developmental disabilities, mental illness or physical disabilities out of institutional care and into community settings.” There is no indication by DHS in the 2016 Implementation Plan Revision that addresses how this “rebalancing” may be funded or how the staffing crisis in general will be addressed. This is part of the reason that this Implementation Plan was filed with the court by the Defendants alone, without a joint motion including the Plaintiffs and Intervenors.

Therefore, as it was during the preparation of the Monitor's Fourth Annual Report, it is impossible for the Monitor to make a finding that the sufficient funds referenced in ¶5 will be available.

The Fourth Annual Report includes dozens of statements from service providers, families and others detailing not only the fiscal problem causing the unprecedented staffing shortage in CILAs and ICFs/DD but also its impact upon the people who live in these homes. These statements remain relevant but will not be repeated herein as the Monitor has received additional, more recent input from countless family members and providers of services and supports to beneficiaries of the Consent Decree. For example:

"We have consistently run 15% (staff) vacancy rates in Residential DSP openings since 2008. This past year it has increased to 25-30%. We do not have enough staff to meet the needs of the clients. This includes consistent difficulty in assisting with: ADLs (activities of daily living), particularly with hygiene and cleaning; community access; managing finances. Because these needs are not consistently being met, the clients have increased incidents of maladaptive behaviors and both clients and families are dissatisfied with services."

"Residents have to get used to different staff in their home each day. Staff have to learn all the outcomes, behavior and counseling plans each time they are in a new house. This affects the residents because they aren't able to build trust with staff as they are not consistently in the home. Multiple family members and guardians have called with complaints about the inconsistent staffing and how that impacts the quality of services."

“There have been multiple staff who have left to work at home health agencies due to pay.”

“We are not in a position to expand our CILA capacity. We are unable to fill the current shifts we have within our current homes. Taking on more homes would mean more vacancies.”

“We have closed three CILA homes and sold buildings to reduce costs. Occupancy in 2008 was nine homes with no home having more than 5 people. In 2015, we operated 6 CILA locations. Occupancy ranges from four to eight people per house.”

“For CILAs and ICFs, we have: downsized staffing due to large yearly deficit; cut back on community outings; trimmed health insurance coverage. Through the admission process, we have declined more difficult individuals with medical or behavioral issues.”

“A huge shortage in staffing directly impacts the program and the quality of time spent with an individual. This situation has created the need to redirect focus to maintaining personal care with ADLs rather than to skill acquisition and skill retention. This directly impacts the agency’s ability to achieve our mission, goals and overall objective. This truly becomes a disservice to the individuals we serve.”

“The work of a Direct Support Professional is both physically and mentally exhausting. While the work can be very rewarding, the impact of staffing shortages and mandatory overtime does not equate to equal pay for equal work. It is far too easy to find a less stressful and demanding job paying an equal or higher rate of pay. Over the past year, the long term effects of the state’s failure to increase the rate of pay has created a reduction in our applicant pool and an increase in our turnover.”

“Our group homes run with minimal staffing, which does not provide opportunities to promote community integration. Scheduled outings are reduced or foregone. This also creates an increased risk to both our staff and individuals. Since the high staffing shortages, the agency has had to implement a system for voluntary, and then ultimately mandatory, overtime to cover all shifts in our group homes. The extra hours staff are working have the potential to increase mental and physical exhaustion, which ultimately increase the risk of injury or errors with respect to personal care and quality of care.”

“Given the current residential and nursing rates, we are unable to support individuals with more advanced nursing or behavioral needs. We neither have the community resources nor support staff to adequately address and manage these individuals.”

“Staff work overtime and extra shifts to meet basic needs and residents are not in the community as they should be. Less consistent caregivers reduce the quality of care and increase the opportunity for error, particularly medication administration errors. Lack of consistent staff and individual attention results in less individual goal progress and increased behavioral issues.”

“This organization would be closed in three months if it operated only on what the State currently pays our organization. “

“To train a DSP requires not only completing the DSP curriculum, but also agency and program orientation. Costs average \$2846.00 per person per training alone. This does not include advertising and time spent reviewing and interviewing candidates. With a turnover of 32%, the CILA program had 1/3 of its staff missing during the last year.”

“Recently the staff who left were good, longer term employees who told us



that they left due to wages. There have been several over the past eight years who were working two jobs and left to find one job that paid a living wage. The reality is that many DSP positions remain open so only basic needs are being addressed. It is impossible to provide the staff time and individualized supports necessary for building community relationships and employment opportunities.”

“We have experienced several times when staffing has dropped so low that we were unable to staff all of our CILA homes for the weekends and have had to close some of them to keep proper staffing ratios. Consumers then have to be relocated to another home for the weekend.”

“The Fiscal Year 2016 reduction in the monthly personal allowance for CILA residents has forced most consumers to spend all their monthly funds on medical items, clothing and hygiene products leaving no money for leisure activities or hobbies which are important to the resident.”

“My daughter has experienced five trips to the Emergency Room over the past eighteen months, is not being provided with the opportunities included in her ISP, has only one staff member on most shifts to meet the needs of all four women who live together and have significantly differing levels of need, and isn’t always provided with healthy food.” (The Monitor regularly addresses such concerns with families, service providers and DDD staff.)

“DSP turnover rate in our CILA homes is 70.32% over the past twelve months. Due to the large amounts of overtime, we have staff that are tired and not at the top of their performance abilities.”

“Consumer behavior and skill development is directly impacted by the revolving door of staff. Staff barely have a chance to review Individual Support Plans or Behavior Plans before they have to move to another

house to fill a vacant shift or they leave. We are in a constant staff training mode. Consumers become confused from having to adapt to various staff personalities and it is almost impossible to gain trust in the person who is responsible for assisting in bathing, toileting, etc. Decisions are focused on who do we have at each house and which staffing option produces the least amount of risk to the consumer and the organization. It is very difficult to go beyond meeting just the consumers' basic needs of food, clothing and shelter. Person centered planning requires one on one interaction with the resident. We try to let residents make individual choices, but often they have to go on group outings. It is even more difficult to deal with unscheduled requests for community access and to visit friends and family. We have reduced the assistance in providing transportation for family visits, especially those out of town. We often struggle to find enough staff to take consumers to medical appointments.”

“Our DSPs are essential to the well being of residents. DSPs provide companionship; assist with daily activities such as shopping, eating, grooming, minor healthcare; facilitate extracurricular activities. As a result of low wages and insufficient benefits, the agency has seen a turnover rate of over 25%. The constant turnover of DSPs is very disruptive to residents as they lose DSPs to whom they have become attached and then must adjust to new staff. This leads to a lower quality of life for individuals as well as more behavioral and mood issues.”

“When Chicago raised the minimum wage to ten dollars, our agency saw its labor pool evaporate. Many applicants are unqualified for the DSP position and DSP positions have taken over ninety days to fill with some remaining vacant for 120 days or more. The decrease in DSPs puts our ability to meet the needs of residents at risk. We have to devote more time and money to staff recruitment, using money that should be going to programs for residents. “

“Person-centered planning has been hardest hit by inadequate State funding. Day program rates cannot even cover basic transportation, let alone what is needed for more individualized activities. Residential rates only provide for a bare minimum level of staffing, which does not allow for individualized activities. We are not reimbursed for the more experienced and skilled level of staff person needed to carry out person-centered plans. Ligas Class Members are seeing their integration into the community curtailed because of the lack of State funding and are not being provided with the services set forth in their Transition Service Plans. Our agency is now faced with the choice of discharging residents, closing programs, or providing less than adequate care, all at the expense of individuals with disabilities.”

“My daughter lives in an ICF/DD (Intermediate Care Facility/ Developmental Disabilities) and has an intellectual disability, seizure disorder as well as limited communication skills. With more direct care staff leaving in recent years, there is a constant flow of new staff who do not know my daughter. Due to my daughter’s limited communication skills and complex medical needs, it takes several months for a new staff member to get to know and understand her. More important, it takes several months for my daughter to feel comfortable with the new staff person who must help her with her most personal needs. My daughter has a calcium deficiency due to seizure disorder medications, which makes it critical that her teeth be properly cared for. New staff do not know how to properly care for my daughter’s teeth and the poor dentition has caused her to lose teeth and has caused the condition of her remaining teeth to worsen. The constant turnover of staff and use of temporary staff has also caused her to suffer increased anxiety as she does not feel comfortable having a new person take care of her until she builds a bond with that person.”

“My son lives in a CILA and has autism, an anxiety disorder and limited verbal skills. Routine and predictability are extremely important for my son

and the lack of these results in his becoming very anxious, fearful and frustrated. Until last year, my son lived in a four-person CILA, but then the operating agency had to consolidate and increase the capacity of its CILAs in order to cut costs. My son moved to a different house for six people and it is anticipated that this house will be increased to eight residents in order to further cut costs. Moving to a new home with more residents is very confusing to him and I am concerned for his safety and the safety of the other residents because it is much more difficult for a single staff person to adequately supervise six or eight individuals with significant developmental disabilities rather than four. Staff work a lot of overtime, resulting in their fatigue, stress and inability to do more than complete basic tasks. They don't have the time, energy or experience to provide the personalized care that my son and other residents need. My son loves activities in the community and used to get out into the community at least once each week, but now only gets once or twice each month. He is often alone in his room and bored, anxious and frustrated. He is being severely limited."

Even more far reaching than individual or large group contacts with the Monitor, and demonstrating widespread concern with the wages paid to Direct Support Professionals (DSPs) who provide what is aptly described as "front line services" to those living in CILAs and ICFs in the community, is the fact that both chambers of the Illinois Legislature passed bills in the fall of 2016 to provide "livable wages" to such employees. This legislation was vetoed by the Governor and an attempted override of the veto was unsuccessful.

As noted above, this crisis goes beyond the money involved in raising wages to the impact of the situation on the beneficiaries of the Consent Decree. On October 17, 2016, the Illinois Senate Human Services Committee held a hearing

on the “Current Status and Future of Compliance with the Ligas Consent Decree and Related Subject Matter.” The Monitor, Plaintiffs’ Counsel, Intervenors’ Counsel and DHS Chief of Staff were invited to speak, as were a parent, two service providers and a direct support professional.

DHS’ Chief of Staff, Fred Flather, reported on the State’s accomplishments in meeting or exceeding the benchmarks required by the Consent Decree for moving Class Members into the community. He also described the ongoing process of defining the “reasonable pace,” as required by the Consent Decree, at which those who choose to live in community-based settings will be able to move to such environments following the six years during which these benchmarks will have been measured. In addition, at this hearing as well as during Parties’ meetings over the past several months, DHS indicated that the agency is not opposed to raising wages for DSPs but that this needs to be addressed within the context of the budget process.

Scott Mendel, Counsel for the Intervenors, spoke about his daughter’s positive experience living in an ICF/DD and described the Intervenors’ participation as a party in the Ligas case. He cited paragraph 4 of the Consent Decree with regard to the State’s responsibility to both honor the residential choices, including ICFs/DD, of all individuals with developmental disabilities and provide the resources necessary to meet the needs of those who choose to live in ICFs/DD. He noted that “Like CILAs, the reimbursement rates provided to ICFs/DD have not increased since March 2008” and that “in those almost nine years costs have increased

dramatically. As a result, the resources provided by the State are no longer sufficient to meet the needs of ICF/DD residents. The insufficient rates are having a severe adverse effect on ICF/DD residents. Residents are not receiving the care they require as a result of low reimbursement rates leading to increased DSP turnover; reduced physical, occupational and speech therapy; reduced community outings; reduced recreational opportunities. This is a violation of the Decree.”

Barry Taylor, Vice President for Civil Rights and Systemic Litigation at Equip for Equality and lead counsel in *Ligas v. Norwood*, represented the Plaintiffs and, following a brief overview of the case and Consent Decree implementation, stated: “While the State has so far met its quantitative requirements under the Consent Decree, we do have serious concerns about the quality of the services being provided....From our perspective, many of the quality issues arise from the low wages paid to Disability Service Professionals or DSPs. The main issues for our clients are: Lack of person-centered planning to allow our clients to live in the most integrated setting...; difficulty placing and supporting people in the community who have significant medical or behavioral needs...; lack of meaningful participation in the community...; lack of integrated, competitive employment opportunities as providers are often taking a one-size fits all approach...because they don’t have sufficient staff to support more customized and integrated employment opportunities.”

The Monitor acknowledged the State's success in meeting the numeric benchmarks in the Consent Decree and highlighted a few of the sections of the Fourth Annual Report as well as the reasons for the finding of noncompliance. The Monitor stated therein that "when committed providers are admitting that their available 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." The Monitor's full testimony is not included herein as the excerpts presented above from service providers and family members eloquently express many of the Monitors' concerns related to the inadequate funding and resulting, unprecedented staffing crisis.

The service providers spoke in detail about the difficulties in maintaining the quality and consistency of services while experiencing: the highest staff vacancy levels in their histories and inability to recruit new staff due to low wages; lack of increase in wages for DSPs in nine years; unprecedented costs of overtime and staff training; staff unable to address individuals' needs. In addition, other written testimony was submitted to this Senate Committee and one of these documents provided to the Monitor noted:

"Of issue is that I/DD provider agencies are having an extremely difficult time hiring and retaining Direct Support Professionals, or DSPs. Specifically, for Ligas Class Members, the inability to hire and retain DSPs has meant there are fewer group home options for those individuals wishing to move out of ICFs/DD as well as a lack of DSPs to help those individuals at home or in a group home receive access to the community-based supports and services that are required

under the Consent Decree. For the roughly 34,000 DSPs working across Illinois, the major issue is that their average hourly wage is \$9.35 or about \$19,488.00 per year. This is less than the federal poverty level for a family of three which has led to over half of the DSPs utilizing public benefits even though they work full time. Without a living wage, there has been and continues to be high turnover among these caregivers, which leads to instability.”

All of this mirrors the individual concerns reported to the Monitor by families, guardians and service providers, as reported herein.

The most compelling testimony at the hearing was provided by the DSP who discussed her ongoing fifteen years of working at a job she loves but in the midst of extremely high staff turnover rates and staff vacancies resulting in inadequate staffing and unsafe situations. She talked about working double shifts for weeks at a time, trying to meet the needs of six individuals at the same time when all have health and other significant needs requiring personal attention “24/7.” She now earns less, after fifteen years of exemplary and personally valued work, than her previous wage of ten dollars per hour which she earned when working for a different State department. Her clearly heartfelt narrative about her own struggles to meet living expenses and medical costs while being unwilling to give up the work to which she is devoted was more illustrative of the crisis than any statistics that might be provided.

As is indicated repeatedly above in this section as well as in paragraphs 4, 5 and 26 of the Consent Decree, the availability and quality of services are critical to



beneficiaries of the Consent Decree. Paragraph 4 refers to the Defendants' obligation to "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..." This points to the need for quality monitoring as well as sufficient funding.

Paragraph 5 states that "Annual budgets submitted by Defendants on behalf of their agencies shall request sufficient funds necessary to develop and maintain services, supports and structures described in the Decree, consistent with the choices of Individuals with Developmental Disabilities, including Class Members." The statements above in this section clearly refer to lack of availability of certain chosen opportunities and activities for individuals, as well as providers' inability to maintain services and structures due to inadequate wages resulting in staff shortages.

Paragraph 26 requires that the "Implementation Plan must, at a minimum: (c) describe necessary resource development activities... to implement the Decree" and (e) identify, based on information known at the time the Implementation Plan is prepared, any services or supports required in Transition Service Plans formulated pursuant to the Decree that are not currently available in the appropriate quantity, quality or geographic location..." This indicates that resource development efforts are a critical component of the Plan and that quality as well as quantity of services must be monitored in order to conduct meaningful reviews of the adequacy of service provision.

Following the Monitor's review of all available documents used by the Bureau of Quality Management (BQM) within DDD, the Monitor expressed concerns that DDD survey protocols had been abbreviated during the past two years and that the process for following up on survey citations was not clear. Therefore, at the Monitor's request, the Monitor, Plaintiffs and DDD met on a conference call in early January, 2017 to discuss the current system of monitoring the quality of services provided in CILAs and day programs. The discussion was informative, addressed questions raised by the Monitor and explained initiatives that will be rolled out through the Life Choices project which are intended to improve the way in which ISC agencies, CILAs and day services are monitored. The Monitor will review a sample of surveys previously conducted by the Bureau of Quality Management, along with any required Corrective Action Plans and follow-ups, to explore the efficacy of current practices as well as make recommendations if it appears that any needed enhancements to the system are not being addressed through current planning.

Problems related to the monitoring of CILAs and the investigation of incidents in some of these homes were brought to public attention during November and December, 2016 when the Chicago Tribune published several articles alleging abuse and neglect occurring primarily in CILAs over the past three or four years. While documenting intolerable treatment of individuals with developmental disabilities who live in CILAs, these articles also brought forth the roles played by inadequate funding, insufficient staff availability and inconsistent, untrained staff in such tragic situations. In addition, it became evident that more effective

oversight on many levels is an absolute necessity. For example, the process and outcomes of quality surveys, quarterly notes by ISCs and investigations must be further evaluated, either as part of the ongoing work of the Life Choices teams and the Quality Committee or as discrete efforts. On a positive note, sessions hosted by the Quality Committee are in process at the time of this writing and are planned statewide to train ISCs specifically in person-centered planning and practices, which is certainly a necessary component of Ligas Transition Service Plans, Individual Service Plans, ISCs' notes and all oversight efforts.

On 12/13/2016, the Joint State Senate and House Human Services Committee held a Subject Matter Hearing to hear testimony regarding abuse and neglect taking place in group homes for individuals with developmental disabilities. DHS Secretary James Dimas acknowledged that the State takes such allegations very seriously and described DHS' efforts, beginning in 2015, "to improve quality for people." He spoke of improvements within the Office of the Inspector General, such as increasing the number of investigators, enhancing the supervision of investigations and discontinuing the participation of providers in their own investigations. An assessment is required of whether or not such improvements are having the desired outcomes and what additional measures are still needed to protect those living in CILAs, including Class Members. Secretary Dimas also outlined a plan to develop "report cards" of the performance of individual service providers to inform the choices of families and advocates in making selections of the most appropriate agencies to provide needed services. There was comprehensive questioning by the legislators and testimony on behalf of Equip

for Equality, The Institute on Public Policy for People with Disabilities, The Arc of Illinois, IARF (Illinois Association of Rehabilitation Facilities) and from the sibling of a woman who lives in a CILA. Some of this testimony, as well as other written comments received thereafter, included:

- “Illinois’ network of community-based services and supports is not operating under the best of circumstances, with reimbursement rates having been frozen by the state for nearly a decade. The single most critical issue facing the provision of community-based services and supports is the inability to recruit and retrain frontline staff. For years, our community has been sounding the alarm about this growing crisis.”
- “It is our hope that these articles will be the catalyst for the changes that need to be made in Illinois.”
- “The widely discussed direct support wage crisis is having a substantial impact on the quality of care delivered in community residences. Agencies are facing unprecedented challenges in recruiting and retaining a direct support workforce which is the backbone of the community residential system.”
- “The problems highlighted in the Tribune article are not an indictment of community living for people with disabilities. There is powerful and unequivocal support for community living in a large body of research that has consistently documented positive experiences of people with developmental disabilities living in the community.”
- “The fact that anyone is hurt or, worse, dies of anything besides natural causes in a group home is unacceptable. I support thorough investigation, corrective action and when appropriate, sanctions. We must also acknowledge that individuals with I/DD are often challenging, and even the best trained staff will never be able to prevent all incidents from occurring.

That said, we are not on a level playing field with community housing (CILA). Reimbursement rates are horrendously inadequate...There is no way that community provider agencies can compete with other minimum wage jobs that are easier and less stressful. Recruitment and retention of quality staff is next to impossible, especially north and west of the city, and the ability to do proper training and implement retention strategies and ongoing training is not possible with the current reimbursement rates...To create living environments in which the health and safety bars are set at the highest possible level, we need the resources to do it.”

One of the provider agencies cited in the first Tribune article had its license revoked prior to the Joint Committee’s hearing. This agency had been surveyed or otherwise reviewed by DDD eight times between 5/17/2011 and 11/14/2016 and there were repeat citations noted in all of the surveys or follow-ups after the one in 5/2012. There were follow-up visits between a few of the surveys and Corrective Action Plans were required at least three times, including during their 11/2016 survey, less than a month prior to the license revocation. Further, EFE’s Abuse Investigation Unit, in 2003, issued a special report entitled “Why Does an Agency That Profited from Exploiting People with Disabilities Remain Taxpayer Funded?” The subject of this report was the same agency, though using a different name, whose license was recently revoked. This report stated that the investigation “revealed extremely serious concerns about the services provided by this agency to individuals with disabilities and the failure of this agency to meet and maintain minimum quality residential and day programming standards.” The conclusion stated, in part: “Only through interventions at the highest level of government and the commitment of sufficient resources to support truly effective oversight, monitoring, investigative, and enforcement mechanisms will the

system by which we protect our most vulnerable citizens, both old and young, become anything other than an illusion of safety and humane care.” Comprehensive recommendations are contained therein which might be useful to consider in addressing current issues.

The Monitor is not making any generalizations based upon having reviewed only one such situation, but the current situation involving this provider does illustrate that even when an established process for quality monitoring is followed and there are uncorrected citations over several years, it can take too long to result in a revoked license. In order to close this loop, the Monitor recommends that BQM explore whether or not there was any documentation in ISCs’ quarterly notes that referred to such problems. Upon learning of the revocation of this agency’s license, the Monitor requested from the Defendants information regarding the Class Members involved and has asked for ongoing updates.

As was the case in January, 2016 and based upon all of the material included in this section, most significantly the escalating impact of the crises upon the quality of services provided to those protected by the Consent Decree, the Monitor once again finds noncompliance with this compliance standard. The Monitor has informed the Parties and Intervenors of the likelihood of this finding.

It is worthy of note that the Ligas Implementation Team continues to include eighteen positions and that the only vacancies at the time of the current report’s

preparation is one position that was vacated on 12/31/2016 and is in the process of being filled and another that will be filled as of 2/1/2017. Members of this team are clearly critical to the Monitor's day-to-day activities and their insights and responsiveness to requests are greatly appreciated.

There is also some positive news included in the Implementation Plan 2016 Revisions document that describes some of DHS' new initiatives such as: increasing the number of Behavior Therapy hours an individual may receive annually under the Waiver; engaging a consultant through a State Mentoring Grant with the Federal Department of Labor to explore opportunities to enhance access to employment services; developing a web-based reporting and search mechanism for tracking vacancies in residential and day programs as well as providers' willingness to develop new service capacity.

## **II. Class Member Lists**

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 is required to include information regarding the adequacy of the PUNS (Prioritization of Urgency of Needs for Services) database.

Paragraph 2 of the Consent Decree requires 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.

As indicated in the Fourth Annual Report, the DDD had at that time established an automated process to add new Class Members to the PUNS list as well as remove those who are no longer eligible. In addition, as reflected in the Implementation Plan 2016 Revisions, DDD conducted, between 5/1/15 and 6/30/16, a special initiative “to ensure information and data on individuals enrolled is accurate, complete and current.” This PUNS Integrity Project involved providing targeted funds to the ISC agencies “to work with individuals and families to bring records



up to date.” It is reported that as of 9/1/2016 96.8% of the PUNS records statewide were current within one year and this exceeded the 95% benchmark that had been established for the end of this initiative.

Prior to the completion of the PUNS Integrity Project, the Parties had begun discussing the need for a more efficient way to track the progression of Class Members who are seeking services to the point of initiation of waiver services. A new comprehensive list was developed, with input from the Plaintiffs and the Monitor and the first such list was disseminated on 7/29/2016. At the request of the Monitor, DDD promptly provided an unscheduled update on 1/13/2017. This new list served as the basis for a discussion regarding further clarification of both the information included and how Class Members move off the list as well as move back on if necessary. The Monitor’s review of this updated list indicated 442 class members to be actively seeking services. In addition, this update provides information as to how long class members have remained on the list following selection from the PUNS waiting list.

<b>Ligas Class Members Seeking Services (1/13/17)</b>	
<b>N=442</b>	
<b>PUNS Selection Date</b>	<b># of Class Members Seeking Services</b>
2012	40
2013	6
2014	47
2016	248
Residing in ICF/DD	101

In the Fourth Annual Report the Monitor had noted delays in initiation of waiver services for class members following selection from the PUNS waiting list. Discussions are ongoing regarding the content of the new list to provide

additional details regarding class members' progression toward placement. The efforts of those involved in this process are integral to the Monitor's ability to identify potential barriers to achieving transitions and to determine Class Members' status toward receiving desired services.

### **III. Transition Service Plans**

Beginning in February 2016 and continuing into FY 2017, the Monitor selected 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, assisted 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.

The Monitor, along with Ms. Miller, reviewed transition plans and service plans for fifty-three (53) class members with a focus on assessing the adequacy of LTSPs as well as whether the class member's preferences and service/support needs were reflected in the initial service plan. It was noted that there had been improvement in the quality of LTSPs over the past year. The Monitor found that service plans reflected the class member's transition plan and for the most part, transitions occurred in a timely manner.

In many instances, the service plan provided to the Monitor was an initial 30-day staffing and therefore did not reflect whether services/supports were fully implemented. The Monitor then requested from DDD additional documents to include the most recent Individual Support Plan and the most recent Individual Service and Support Advocacy (ISSA) Visiting Note completed by the Independent

Service Coordinator (ISC). For those class members who had a new ISP developed since transition, that ISP was provided to the Monitor as documentation of one of the required four ISC visits per year for 31 class members (58%) and ISC visit notes were provided for 35 class members (67%). For some class members, both types of documents were provided.

As set forth in the ISSA Guidelines issued by DHS, Independent Service Coordinators are expected to conduct a minimum of four visits per year: one annual visit for participation in the development of the class member's ISP; one annual visit to assist the class member in completing the Consumer Satisfaction Survey; one annual visit to the class member's day program site; and one annual visit to the class member's residence. As indicated in the Guidelines, "Besides participating in the development of the annual service plan, ISCs will review the service plan for adequacy in meeting the needs and preferences of the individual...The priority goal is that issues of health, safety, and meaningful programming are receiving attention." Based on review of the ISC visit notes, the Monitor determined that only 14 (40%) of the 35 visit notes provided contained a substantive description of whether, per the Guidelines, "the ISP contains identified outcomes for the person that substantially meet all of the person's needs; services are being provided in accord with the ISP; and progress toward outcomes is evident (or if not evident, the team is revising the ISP in order to promote progress toward outcomes)." For example, many visit notes contained general statements without reference to specific outcomes, such as:

- “Goals are reviewed monthly and revisions are made as necessary. In addition, the ISP team meets annually to discuss goal performance and recommendations are made based on goal performance.”
- “[Class Member] is making some progress on objectives. Data was somewhat limited, however [Class Member] reported working on many of them and continues to need to work on possible medication side effects and following a budget.”
- “[Class Member] has a monthly progress note in his file for each month. His goals are updated every three months. His plan is being revised as needed.”

On a positive note, in at least one case, the visit note reflected “monthly summaries were not provided so progress could not be assessed. Data for September and October was collected during the visit by the facilitator. She met her objectives for both of these months.” The ISC flagged the lack of monthly summaries as a need for follow-up action. For another individual, visit note indicated that provider agency Qualified Intellectual Disability Professional (QIDP) monthly notes were missing for February 2016 through April 2016. The ISC flagged this for follow-up.

As noted above, this project was initiated to evaluate the adequacy of LTSPs, to determine whether or not they serve as foundations upon which individual service plans are developed, and assess whether services are being provided as described in the ISP and whether progress toward outcomes is evident. In order to review implementation of service plans, the Monitor requested ISC visit notes for each person in the sample to determine whether these monthly notes serve

as a measure of achievement of outcomes identified in class members' ISPs. Overall, the Monitor found that while visit forms expect the ISC to indicate whether progress is being made towards outcomes, there was absence of an analysis or a comparison of progress to the previous quarter(s) on which to base the determination of progress or lack thereof. Therefore, based on the finding that only 40% of the visit notes contained the necessary information on which to measure implementation and progress toward personal outcomes, it is recommended that emphasis be placed on addressing this issue as part of ongoing initiatives to enhance quality monitoring as described in section I above.

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

Paragraph 17 of the Consent Decree requires 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-Based settings consistent with their Transition Service 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 the list defining this category. To date, the Defendants have consistently exceeded the target numbers with placements totaling more than 300 beyond the target for 12/1/2015, by which time 1255 of 1446 then active Ligas ICF/DD Class Members had transitioned to the community. As of 12/31/2016, 1363 of 1481 active Ligas ICF/DD Class Members had transitioned to the community. Of these 1363 Class Members, 1332 went to CILAs and the Monitor has requested additional details related to the transitions.

The Monitor applauds the efforts involved in exceeding the benchmarks and will continue to work with the Plaintiffs and Defendants to facilitate the transitions of Ligas ICF/DD Class Members who choose to move to the community. All Class

Members must be offered a variety of options and opportunities in order 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 Parties in tracking how such choices are facilitated, particularly in consideration of the obstacles, as discussed in section I. Resources and Capacity herein, related to both the maintenance of existing community services and further development.

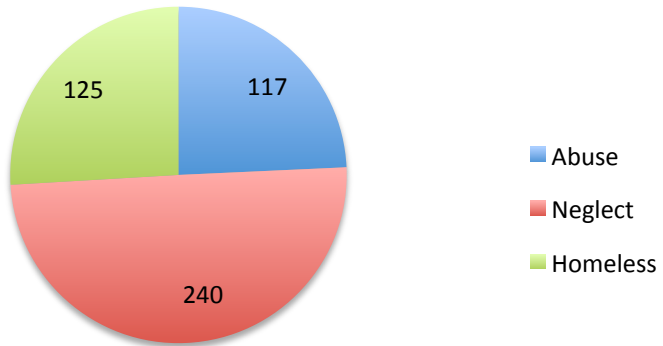


## V. Crisis Services

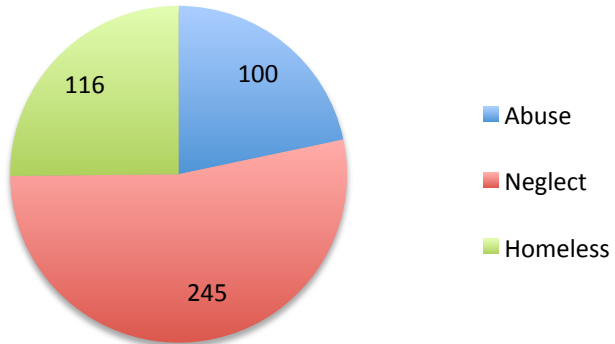
As indicated in ¶21(a)-(b) of the Ligas Consent Decree, “an individual is in a situation of “Crisis” if he or she is at imminent risk of abuse, neglect, or homelessness. The provision of interim emergency services (including interim placement in an ICF-DD where no placement in a Community-Based Setting 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, 2015 through June 30, 2016 indicated that 506 crisis services requests were received and reviewed by DDD with 482 requests approved. Denials of crisis services requests were due to crisis criteria not being met and/or determination of lack of clinical eligibility. According to the crisis data, between 7/1/15 and 6/30/16, one hundred seventeen (117) crisis requests received were classified as abuse, 240 were classified as neglect, and 125 were due to the individual being homeless.

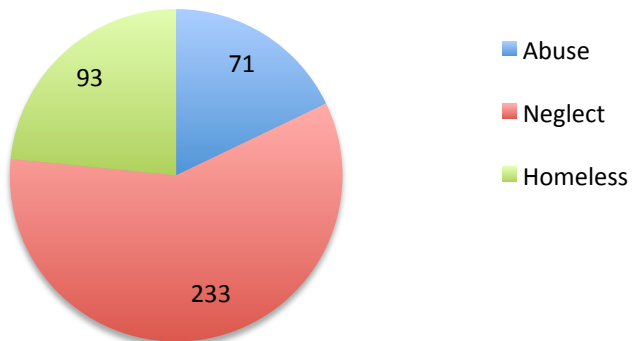
**Classification of Approved Crisis Requests  
July 1, 2015-June 30, 2016**



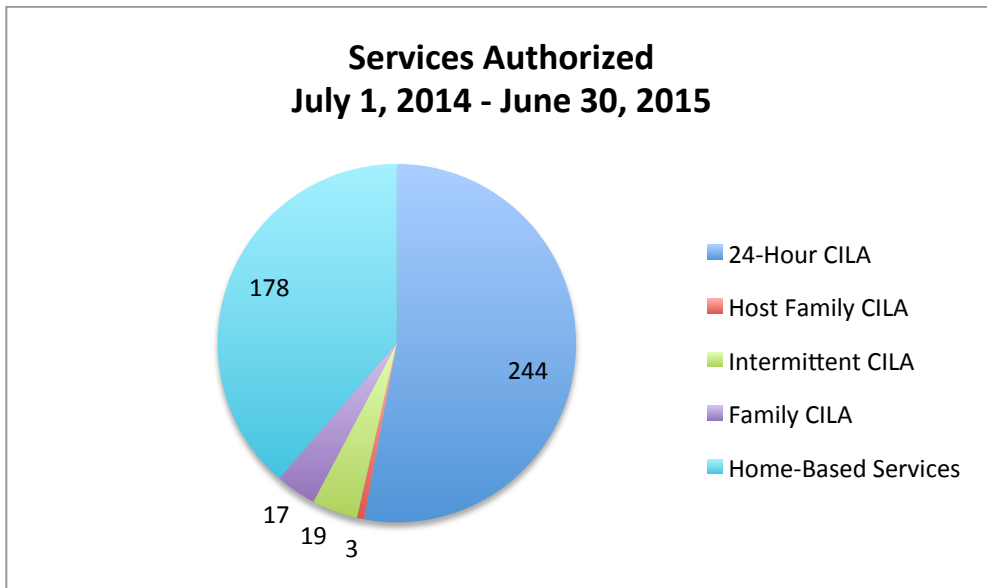
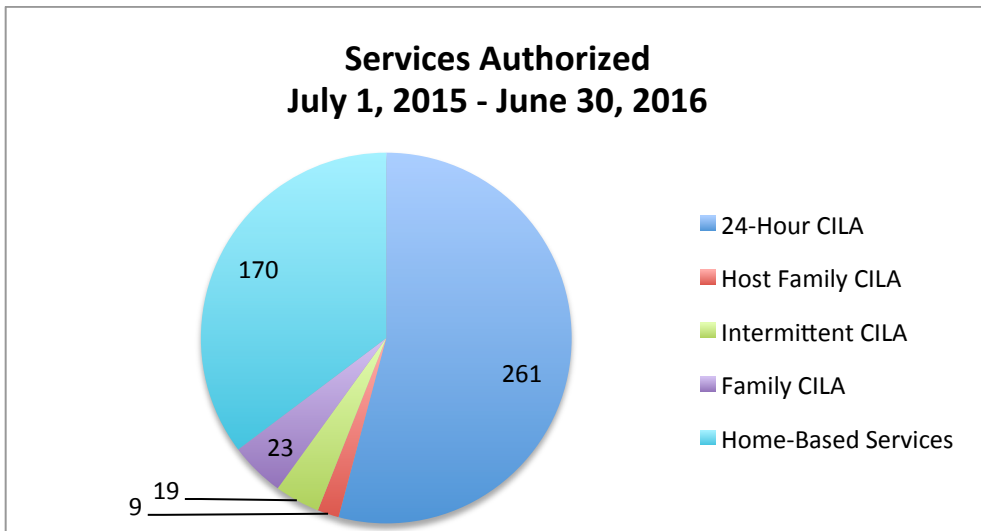
**Classification of Approved Crisis Requests  
July 1, 2014-June 30, 2015**

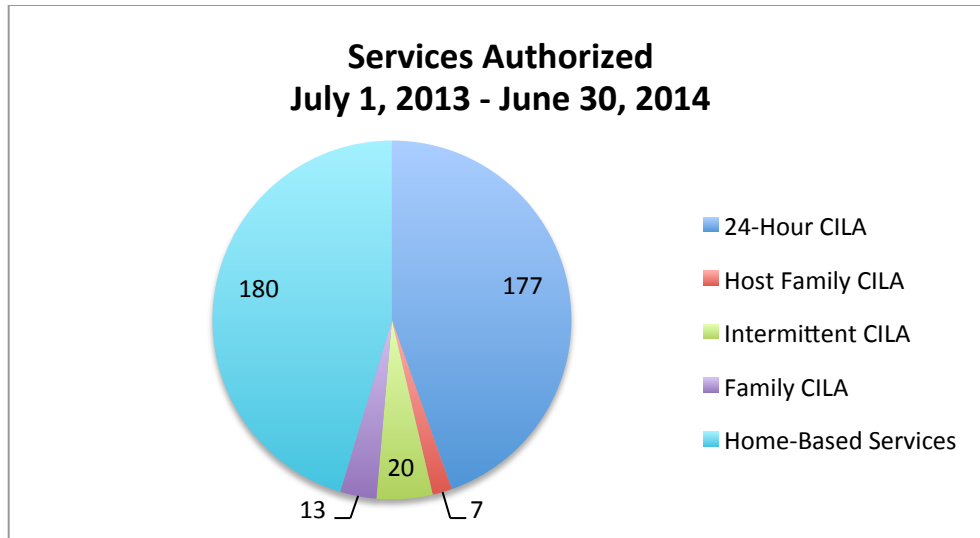


**Classification of Approved Crisis Requests  
July 1, 2013-June 30, 2014**

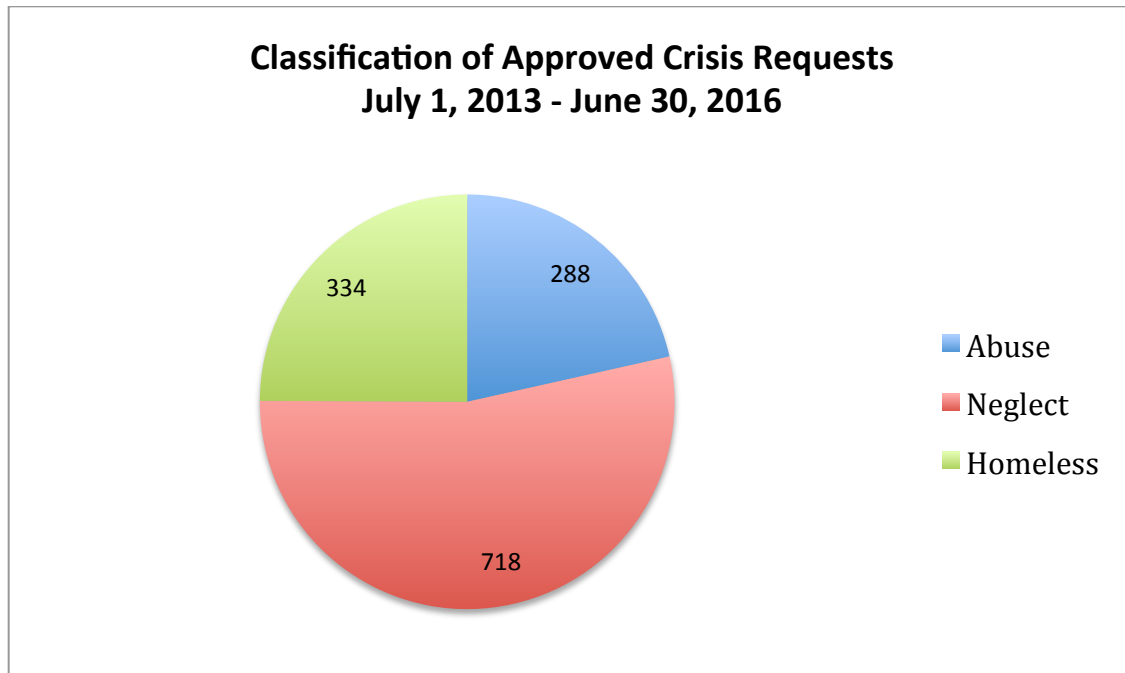


Services provided to class members in crisis included four types of CILA (Community Integrated Living Arrangement) options: 24-Hour CILA, Host Family CILA, Intermittent CILA, and Family CILA, in addition to Home-Based Support Services (HBS). Of the 482 crisis requests approved, 261 were approved to receive 24-Hour CILA, 9 were approved to receive Host Family CILA, 19 were approved to receive Intermittent CILA, and 23 were approved to receive Family CILA. Home-Based Support Services were approved for 170 class members:

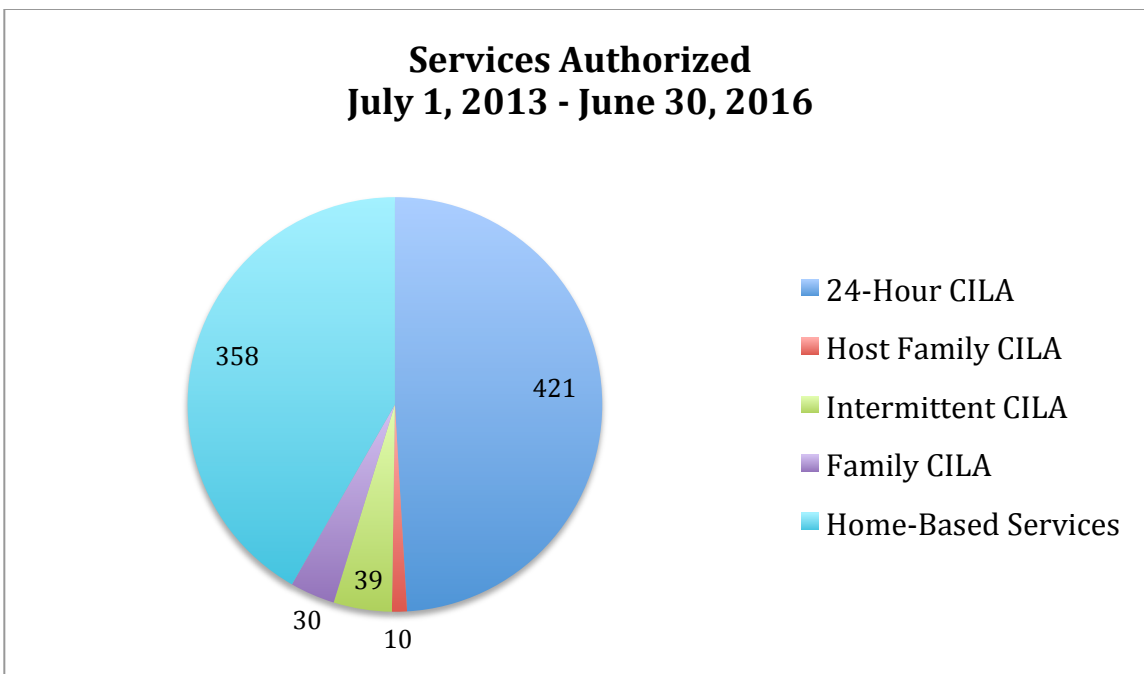




Combining the three reporting years (7/1/13-6/30/16), a total of 1340 crisis requests out of 1415 requests received have been approved by DDD.



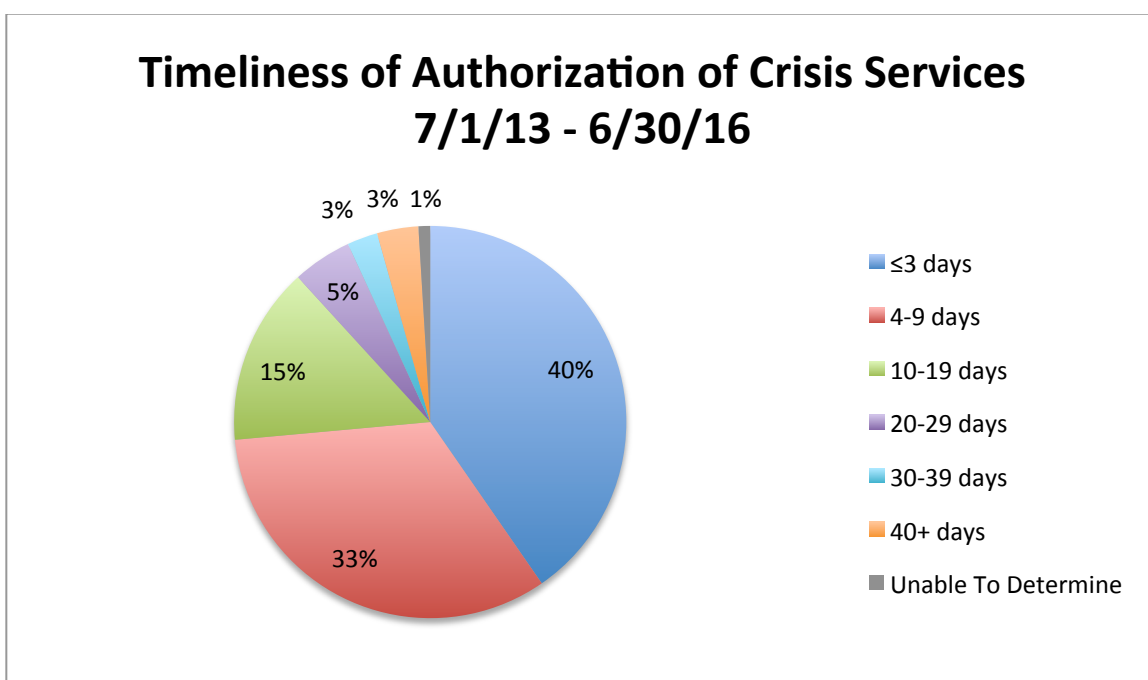
For this same reporting period (7/1/13-6/30/16), services were provided to class members in crisis within four types of CILA (Community Integrated Living Arrangement) options:



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. For the past three years, the Monitor has analyzed class member information and data from all crisis requests received and reviewed by the Defendants and determined to meet the requirements for crisis services. From the Monitor’s analysis, improvement was noted in the timely review of the crisis packets upon receipt by the Defendants.

After crisis status was confirmed, 40% (545) of the Class Members who were found to be in crisis received some service within a 24-72 hour period. The following two charts represent the Monitor’s analysis with a view of the three years in comparison and the three years in summary.

Timeliness of Authorization of Crisis Services	FY 2013-2014		FY 2014-2015		FY 2015-2016		Overall 2013-2016	
	N=397		N=461		N=482		N=1,340	
24-72 hours	107	27%	218	47%	220	46%	545	40%
4-9 days	122	31%	151	33%	175	36%	448	33%
10-19 days	74	19%	64	14%	60	12%	198	15%
20-29 days	36	9%	15	3%	15	3%	66	5%
30-39 days	15	4%	6	1%	3	1%	24	3%
40+	35	8%	5	1%	6	1%	46	3%
Insufficient Data	8	2%	2	1%	3	1%	13	1%



As presented above, data from the most recent reporting period (July 1, 2015 to June 30, 2016) shows that 46% of the class members who were found to be in crisis, received some service within a 24-72 hour period after their crisis status was confirmed; for (36%) services were initiated between 4 and 9 days; 12% received services between 10-19 days; 3% received services between 20 and 29 days; services were not initiated for 2% of the class members for more than a month; and for three class members, data was insufficient to include in the

analysis. While the past two years show improvement over FY 13/14, there are still fewer than one-half of the individuals who were found to be in crisis receiving some services within the 24-72 hours agreed upon timeline. The Monitor recommends that the Parties address this situation at an upcoming Parties' meeting.

Review of the data associated with the 1,340 crisis requests received and reviewed between July 1, 2013 and June 30, 2016 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. In the Fourth Annual Report, it is noted that the Monitor raised concerns as to the adequacy of safety plans wherein the class member in crisis is not in a permanent or stable situation (e.g., jail, psychiatric hospital, nursing home). It was recommended that the Defendants and Monitor confer to clarify criteria for determining adequacy of a safety plan. Discussions have taken place during Parties' Meetings and on other occasions throughout the past year during which DDD reported that this issue is being addressed and progress will be reported at upcoming Parties' meetings.

The Fourth Annual Report reflects an analysis of crisis data to determine the relationship between crisis applicants and the PUNS list. As noted in that report, some individuals in crisis situations were not selected for services because their PUNS enrollment was out of date and/or did not reflect current circumstances. Also included therein, the PUNS Integrity Project had been implemented to bring

and maintain PUNS enrollments current. That project has been concluded successfully.

As noted in the Ligas Implementation Plan 2016 Revisions (filed on November 16, 2016), in addition to raising the question of the adequacy of crisis safety plans in the Fourth Annual Report, the Monitor also expressed concern that nearly half (49%) of the individuals with approved crisis placements were on the PUNS waiting list for three years or more. Per the Monitor's recommendation in the Fourth Annual Report, DHS began during 2016 to discuss criteria for determining adequacy of a safety plan and considering the relationship between the PUNS waiting time and crisis requests. Conversations among the Parties will be initiated during the second half of fiscal year 2017. The chart below reflects the length of time of PUNS enrollment prior to receipt of the crisis request for fiscal year 2015/16.

<b>FY15 and FY16 Approved Crisis Placements and Length of time on PUNS Waiting List</b>		
<b>Time Period</b>	<b>Number of Placements</b>	<b>% of Total</b>
One Month or Less	69	7%
Over 1 Month to 1 Year	212	22%
1 to 2 Years	107	11%
2 to 3 Years	82	9%
3 to 4 Years	57	6%
4 Years or More	326	34%
No Data Report	98	10%
		<b>N=951</b>

As presented in the chart above, 40% of individuals with approved crisis services were on the PUNS waiting list for 3 years or more. This demonstrates a 9% improvement over the previous year.



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 ¶22 of the Decree will transition to the community and be referred to as Waiting List Class Members. A specific schedule for such transitions to community services or community-based settings is delineated in ¶22 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

The Implementation Plan incorporates criteria for the prioritization of selections of Waiting List Class Members and within each prioritized category selections are to be made according to the length of time the Class Member has been on the PUNS list.

¶23 of the Consent Decree requires that following June 15, 2017, Waiting List Class Members “shall receive appropriate Community-Based Services and/or placement in a Community-Based Setting such that they move off the Waiting List at a reasonable pace.” During the past year, the Plaintiffs, Defendants and the Monitor have initiated the process to define this “reasonable pace.” Discussions are ongoing in order for implementation to begin by the required date.

## **VII. Outreach**

Paragraph 25 of the Consent Decree requires that Defendants “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.”

The Defendant’s outreach efforts are defined comprehensively in the Implementation Plan 2016 Revisions and are divided into a “Community Outreach” section and a section titled “Outreach to Persons in ICFs/DD.” In order to address the issue of identifying Potential Class Members residing in ICFs/DD (excluding those living in ICFs/DD who had already submitted written requests to be excluded from the Class), the Defendants secured the services of the Council on Quality Leadership (CQL) and the completion of that project resulted in a report that was shared with the Monitor and Parties in April, 2016. In that report, CQL identified 123 individuals who chose to become Class Members and were added to Class Members List. In addition, 55 individuals who had requested extra time to consider their options were given information regarding the appropriate ISC agencies to contact if desired in the future. Upon request of the Monitor, DDD staff agreed to contact the 55 individuals noted above and to provide follow-up information regarding the 123 individuals who were added to the Class list.

It is important to note that in order to become a member of the Waiting List Class, people need to make a record with the State confirming their desire for community services. People who are already on the PUNS list are deemed to have made such a record and are part of the Class.

## VIII. Implementation Plan

¶26 of the Consent Decree requires that “the Defendants, with the input of the Monitor, Plaintiffs, Class Counsel, Intervenors and Intervenors’ Counsel shall create and implement an Implementation Plan to accomplish the obligations set forth in the Decree,” and ¶28 requires that this plan be “updated and amended annually, or at such earlier intervals as Defendants deem necessary or appropriate.”

At each scheduled Parties’ meeting, the Defendants provide verbal updates of the Plan’s activities, as requested by the Parties, Intervenors and Monitor, and discussions are focused upon the areas deemed most significant at a given time.

The Implementation Plan updates and proposed revisions are provided by the Defendants to the Plaintiffs, Intervenors and Monitor for Consideration. Each year, through 2015, negotiations have taken place and resulted in jointly developed revisions being agreed upon before being submitted to the Court. However in 2016, despite significant efforts by all involved, the Parties could not reach agreement as to some of the Plan’s content. As referred to in section I (Resources and Capacity) herein, the Consent Decree requires at ¶26 that a list of items that must be included in the Implementation Plan. Two of the required items are:

(c) describe necessary resource development activities...to implement the Decree;

(e) identify, based on information known at the time the Implementation Plan is prepared, any services or supports required in Transition Service Plans formulated pursuant to the Decree that are not currently available in the appropriate quantity, quality or geographic location;

The Monitor did not recall the requirement of ¶26(c) until preparing the current report and therefore did not bring it to the Parties' attention. This is not being cited as noncompliance with the Decree. Rather, it is illustrative of why there was no joint submission to the Court of the 2016 Revisions. The Plaintiffs and Intervenors agreed to disagree with the Defendants on the topic of including information therein regarding necessary "resource development activities."

Regarding ¶26(e), the Monitor has initiated discussions related to Quality Monitoring and, while Defendants have agreed to participate in such conversations, there has been some disagreement as to whether the Consent Decree includes any requirements related to this area. In order to identify a lack of services available of the appropriate quality, there would need to be a robust system to measure the quality of existing services. This matter is also discussed in the above section I.

Whether or not issues are included in the Implementation Plan or agreed upon, the Monitor appreciates the cooperation of the Parties and Intervenors in thoroughly addressing issues upon which implementation of the Consent Decree depends.

## **IX. Data Reports**

Paragraph 33 of the Consent Decree requires that the Defendants, not less than every six months, “provide to the Monitor, Plaintiffs, Class Counsel, Intervenors and Intervenors’ Counsel and make publicly available, a detailed report containing data and information sufficient to evaluate Defendants’ compliance with the Decree and Defendants’ progress toward achieving compliance.”

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, clarify data and address concerns related to documents they have prepared.



## **CLOSING COMMENTS**

The Monitor remains indebted to her predecessor, Tony Records, who worked with the Parties to create the systems for ensuring compliance with the Consent Decree and shared with the current Monitor his expertise and experience. Gratitude is also expressed to the Parties, families, Class Members, Intervenors, advocates, providers of services, colleagues and others who have shared their insights, intelligence and inspiration. The Monitor looks forward to engaging in continued shared efforts to assure that all of those who benefit from the Consent Decree achieve their chosen goals.

Respectfully Submitted:           Ronnie Cohn  
  Court Monitor  
  ligas.monitor@gmail.com