

***STANLEY LIGAS, et al. v. JULIE HAMOS, et al.***

**First Annual Report of the Monitor**

**September 27, 2012**

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**Section 1 – Introduction**

This report is respectfully submitted to the Court, the Parties and the Intervenors in accordance with the Consent Decree (Decree) approved and filed by the Court on June 15, 2011. Specifically, 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 Monitor has engaged in numerous activities consistent with Section XIV (Monitoring and Compliance) of the Decree. There have been seven parties' meetings since the approval of the Decree. During each of these meetings, the Monitor has given a verbal report of progress and concerns regarding compliance as well as a review of activities. The Monitor has also met with and talked to counsel and representatives of the parties and intervenors separately on an ongoing basis. No prior drafts of this report or any part of this report have been submitted

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<sup>1</sup> Consent Decree, Section XIV, ¶34, at Page 19.

to the parties, intervenors or anyone else. This report was served by hand to the Parties and Intervenors at the scheduled Parties' meeting of September 27, 2012.

This report is organized in five sections. Following the introduction is a section describing the activities of the Monitor during the past year and anticipated activities for the next year. This is followed by a brief and general description of actions taken by the Defendants during this period. The next section is the primary section, which includes a sequential description of activities and findings listed in order of requirements of the Decree and as listed in the established Compliance Standards developed by the Monitor in accordance with the Decree.<sup>2</sup> Finally, the Monitor has included some overall comments designed to communicate a broad description of progress and successes thus far, as well as anticipated possible roadblocks to compliance in the future.

There has been one instance, on May 1, 2012 when the Monitor notified the Defendants and Plaintiffs' counsel of non-compliance with ¶21. (c) of the Decree (Crisis Services). In accordance with the Compliance provisions of the Decree,<sup>3</sup> the Monitor met and conferred with the parties to discuss the necessary actions to achieve compliance. The defendants are now implementing the action steps that were developed as the result of this process. (See section on Crisis Services on page 22-23 for further details). Other than this one instance, there have been no other notices or written findings of non-compliance.

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<sup>2</sup> Consent Decree, Section XIV, ¶32, at pages 17 and 18.

<sup>3</sup> Consent Decree, Section XIV, ¶35, at page 19

## **Section 2 - Activities of the Monitor**

The Monitor was appointed by the Court on July 19, 2011 and started monitoring activities on August 3, 2011. During the past year, the Monitor has engaged in numerous activities designed to initiate and encourage necessary compliance-related actions, assist the Defendants in the implementation of the Consent Decree requirements, facilitate communication between the parties, engage in activities to inform the public about the requirements of the Decree and evaluate overall compliance.

At the outset, it is important to state clearly that the Monitor has received full cooperation and support from the Defendants, including the Departments of Human Services and Home and Family Services, the Governor's office, the Attorney General's office and, in particular, the management team and staff at the Division of Developmental Disabilities (DDD). DDD has provided the Monitor with unfettered access to program staff, class members, class member records and requested information and documents. Plaintiffs' counsel and representatives as well as counsel for the Intervenors have also been readily available and responsive to the Monitor whenever called upon. In all of the parties' meetings, discussions have been productive and on point toward the goal of compliance with the Decree.

The Monitor has also experienced full cooperation and support from the community service providers, ICF/DD facility staff, advocacy organizations and family associations throughout the state of Illinois through the provision of information, facilitation of meetings and direct input on issues relating to compliance activities.

Class members, as well as their guardians and families have also been forthcoming and responsive to the Monitor and continuously expressed a willingness to

participate in activities and share their experiences in order to assist the Monitor in evaluating compliance.

Activities of the Monitor over the past year include the following:

- ✓ The Monitor held initial separate meetings with all counsel to discuss expectations and obtain various perspectives on challenges pertaining to compliance activities.
- ✓ The Monitor has facilitated each of the parties' meetings. These meetings were held on 8/22/11, 9/19/11, 10/24/11, 12/5/11, 1/23/12, 3/29/12 and 6/21/12. These parties meetings are now being scheduled routinely each quarter in order to maintain regular line of communication among the parties and to document progress and concerns on a timely basis. To increase efficiency and productivity, these meetings have now been bifurcated to include full participation of the parties and Intervenors for discussion and input relating to paragraphs 4-10, 25 and 45 of the Decree and only class counsel and defendants' participation with regard to the remaining provisions of the Decree.
- ✓ Initial and continuous meetings have been conducted with key staff at DDD and DHS who have specific responsibilities relating to implementation of compliance related activities. The Associate Director of DDD has been the key liaison with the Monitor in facilitating meetings, document production and development and coordination of compliance activities.
- ✓ The Monitor has devoted a significant amount of time and effort to provide information sessions across the state to class members, potential class members, families, guardians, community service providers, advocacy organizations, ICF/DD providers, PAS agencies and other stakeholders. These information sessions provided an overview of the Decree and Implementation Plan as well as an update of compliance activities and ways stakeholders can play a vital role in providing information and feedback on *Ligas* related issues. Audiences of more than twenty of these information sessions have included more than 1,800 individuals.
- ✓ Monthly meetings are held with the DDD Director to review progress and challenges related to implementation activities designed to develop strategies to address current issues. The Monitor has also had several meetings with the DHS Secretary to provide an update of activities and any concerns about overall compliance.

- ✓ The Monitor has also met on several occasions with the Governor's office to provide an overview of activities and discuss any overall compliance concerns.
- ✓ The Monitor has reviewed hundreds of documents provided by the defendants, class counsel, service providers, PAS agencies, advocacy organizations and families that have provided significant information, insight and perspective to compliance activities and challenges.
- ✓ The Monitor has reviewed all information on the defendants' various websites relevant to compliance activities and policies that relate to the Decree. The Monitor has worked directly with DDD staff to review and modify information on the *Ligas* page or the DDD website.
- ✓ The Monitor has provided his telephone and email contact information widely across the state in order to hear directly from class members, families, guardians, service providers and PAS agencies about questions and concerns relative to implementation of compliance related activities. As a result, there have been numerous inquiries and concerns received which require specific follow-up and clarification with the defendants. This process has helped clarify many policy questions that have emanated as result of new compliance activities.
- ✓ In accordance with the Decree, the Monitor developed, with input from the parties and intervenors, Compliance Evaluation Standards.<sup>4</sup> These Standards were completed on July 17, 2012. These Standards include agreed-upon standards as well as the specific methodology the Monitor will utilize in measuring compliance.

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<sup>4</sup> ¶32 of June 15, 2011 Consent Decree at page 17

### **Section 3 - Overall Activities of the Defendants and Parties**

Implementation of activities to foster compliance with the Decree has required the infusion of significant resources and personnel efforts by the defendants. It is important to state at the outset that the developmental disabilities system in Illinois has, through the past years, been fraught with inadequate funding, slow growth of capacity, shortages of staff and a weak infrastructure. Within two months after the approval of the Decree, a new Director of DDD was hired. During the same period, the defendants entered into two other major consent decrees and announced the closures of two state-operated developmental centers.

Including those individuals in crisis, individuals on the waiting list and those in ICFs/DD who have requested home community based services, there are currently approximately 12,000 *Ligas* class members. This overall scenario presented the defendants with a seemingly Sisyphean task of entering into a new way of responding to the needs of people with intellectual and developmental disabilities.

The defendants, however, through planning and coordination, have undertaken a systematic approach toward compliance with the Decree. A team within DDD was assigned to specific tasks related to various requirements of the Decree. A *Ligas* budget was developed. New resources were created or identified to support development of community-based supports. A *Ligas* website was established. The *Ligas Implementation Plan* was drafted and negotiated with the parties and intervenors. Policies were developed and/or modified to address *Ligas* requirements. Communications about *Ligas*-related activities were sent to families, class members, community services providers and PAS agencies. This report, in the section immediately below, provides specific information about these activities. In many instances, these activities have resulted or will result in compliance within the timeframes established in the Decree. In some instances, as specified below, compliance with the timeframes of the Decree has been slow or

will be difficult to achieve within the timeframes prescribed unless additional steps are taken. These strong efforts of the defendants, however, have established a foundation upon which substantial compliance can be obtained and sustained over time. It is important for the parties to appreciate that this is the end of the first year of at least a nine year period of implementation of compliance activities.

During this first year of implementation, the parties and intervenors have also collectively contributed toward resolution of issues as they arise. Through the parties' meetings as well as informal communication methods, the parties and intervenors have effectively negotiated timeframes, compliance documents (to include the Implementation Plan and Outreach RFP) and have worked well together to clarify compliance issues.

The Monitor has served as a facilitator with the parties toward productive resolution of issues. With regard to the defendants, the Monitor has assumed a more hands-on role as compliance activities have evolved. This means at times advising the defendants through the offering of suggestions, and, when necessary, the Monitor will goad the defendants toward the direction needed to achieve sustained compliance. This method of mentoring and consultation will continue as long as there is continued priority on compliance with the Decree and measurable progress.

## **Section 4 – Compliance Requirements and Activities**

This section provides a specific review of the compliance requirements in each of the nine major areas of compliance, which include the following:

1. Resources and Capacity
2. Class Member List(s)
3. Transition Service Plans
4. Transition for Class Members in ICFs/DD
5. Crisis Services
6. Transition for Class Members on Waiting List
7. Outreach
8. Implementation Plan
9. Data Reports

Each area of compliance is listed below in a separate section that includes: a description of the requirements in the Consent Decree; timeframes or deadlines for compliance; related activities described in the Implementation Plan and; the status of implementation of compliance activities by the defendants. In accordance with this provision, this section is considered by the Monitor as the primary measure of compliance with the Decree. For some of the requirements, the timeframes for implementation of the specific timeframes have not yet transpired. In these instances, the Monitor will report on activities that have occurred so far and, where appropriate, the likelihood that these actions will lead to timely compliance.

There are also findings in two other distinct areas of the Decree including services to named plaintiffs and dispute resolution.



## **Resources and Capacity**

The Decree requires that resources for community services to be provided consistent with the choice of a class member and the requirements of paragraphs 17 through 19 and 21 through 23 of the Decree. Resources necessary to meet the needs of individuals with developmental disabilities who choose to receive services in ICFs/DD shall be made available and such resources will not be affected by Defendants' fulfillment of their obligations under the Decree. Funding for services for individuals 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. Amendments to the state Medicaid plan will continue to include ICF/DD services as an alternative choice for long term services.<sup>5</sup> Annual budgets will be sufficient to fund the services necessary to comply with the Decree consistent with the choices of individuals with developmental disabilities, including class members.<sup>6</sup>

The Implementation Plan calls for a continuation of activities to develop new community services providers and the voluntary conversion of ICFs/DD to community-based services.<sup>7</sup> The Implementation Plan also calls for the development of annual budget proposals to incorporate the necessary resources to carry out the provisions of the Decree. The Plan also includes resources for a listing of specific contractual agreements necessary to address the anticipated increase in demand for services, additional DDD staff to be hired in order to manage compliance and prepare compliance-related reports and funding for direct services for class members as they are identified to receive community services.<sup>8</sup>

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<sup>5</sup> ¶ 4 of June 15, 2011 Consent Decree at page 7

<sup>6</sup> ¶ 5 of June 15, 2011 Consent Decree at pages 7 and 8.

<sup>7</sup> Ligas Implementation Plan, 12/15/11, Section IV, Page 13.

<sup>8</sup> Ligas Implementation Plan, 12/15/11, Section X, Page 20-22.

In order to comply with the provisions of the Decree regarding resources, the defendants engaged in numerous activities. These activities include the following:

- A *Ligas* budget was developed for Fiscal Year 2013 and beyond. The DDD Director presented a six-year budget to the parties and intervenors at the December 5, 2011 parties' meeting. The projected budget information presented reflected the needed growth in community capacity called for in the Decree. The budget planning assumptions were also included in the presentation. There were no changes projected in the budget levels for people living in ICF/DD settings. The *Ligas* budget totals \$38.9 million in FY13. The anticipated *Ligas* expenditures for the six-year period from FY12-FY17 is \$456.4 million. Six months later, it was announced that the Governor reduced the overall budget by 4%. The DHS Secretary assured the parties that there will be no specific cuts to services. It is expected that these reductions will be absorbed through delayed start-up and reduced annualization of new services.
- Since then, Department of Human Services (DHS) has recently announced instituted changes in the reimbursements as well methods and standards for establishing payments for home and community-based services, particularly targeting small (1-4 person) Community Integrated Living Arrangements (CILA). Many of these changes are designed to realign the prior disincentives in the reimbursement rate structure for smaller community homes. These changes include the following:
  - An increase in the staff fringe benefit percentage for all CILAs from 20% to 25%.
  - Modification of direct care staffing funding formulas for 1, 2, 3 and 4 person homes;
  - Increase minimum direct care staff coverage by two hours per day;
  - Update housing allowances for CILA sites with a capacity of four persons or fewer;
  - Adjust funding for vehicle purchases and vehicle operation for CILA sites with a capacity of four persons or fewer; and
  - Implement funding formula changes in nursing services reimbursement for medication administration and nurse monitoring.

These changes will be effective October 1, 2012. It is estimated that these combined changes will result in an increase of \$19.30 million in new annualized state expenditures.

- A new *Ligas Implementation Team* was funded and is being assembled. Positions for this team includes the following:
  - Compliance Coordinator – This position is currently vacant and the work is being shared by the DDD Associate Director and a senior staff within BTS.
  - Program and Data Support Staff – This position has not yet been established.
  - Bureau of Quality Management Staff (7) - Three positions were filled in FY12. One position was posted and qualifications have been approved. Two positions are being filled through the state attrition process.
  - Bureau of Transition Services Staff (4) – Two positions were filled in FY12. Two positions have not yet been posted.
  - Appeals Unit Staff – Position was filled in FY12
  - Rates Section Staff – Position was filled in FY12
  - Medicaid Waiver Staff (3) - Two positions were posted and candidates were identified and are pending final approval.
- Budget allocations were identified for contract services and service enhancements for PAS agencies.
- Grants for PAS agencies were enhanced to facilitate *Ligas*-related activities.
  - Effective July 1, 2012 grants to PAS agencies for intake and screening have been increased across the board by 10%. This increase is to allow for the expected increase in work demand.
  - Reimbursement funds for PAS agencies work in PUNS-related activities will be structured to allow for expedited payments.
- Proposed amendments were submitted to the Center for Medicare and Medicaid (CMS) for the expansion of the Medicaid Home and Community Based Services (HCBS) Waiver. On June 13, 2012 the defendants submitted application to increase the adult waiver capacity from 15,920 individuals to 18,200 individuals. This increase was designed to allow for sufficient increase in capacity to serve the number of new class members called for to comply with the Decree. These requested amendments were approved by CMS on September 20, 2012. The defendants and the Monitor will track capacity growth closely and, if necessary, the defendants will submit additional amendments in the future.

- The DDD Director has pledged to re-assemble a workgroup of stakeholders to evaluate the rates and rate structure for funding of home and community-based services.

The Monitor commends the defendants for the many steps taken as described above in order to identify resources to support expanded community-based capacity to comply with the Decree. While each one of these efforts are of consequence and will play a significant role in moving implementation forward, still more needs to be done. The Monitor has the following specific concerns with regard to resources:

- It is important that the full *Ligas Implementation Team* needs to be hired and functioning in order to meet the many challenging demands of the Decree and Implementation Plan. As listed above, only 8 of the 18 new staff positions have been filled. It is absolutely necessary for the defendants to expeditiously move forward and hire and train these new staff. Overall, DDD is already seriously understaffed to implement all of its responsibilities along with the added responsibilities that the implementation of the Decree presents.
- Although reassembling a community rates workgroup is an important step toward rebalancing the funding and rate structure of home and community-based services, this issue must be given top priority and move forward with vivacity. Even with the recent rates enhancements listed above, the overall rates for home and community-based services in Illinois remain to be among the lowest in the country. With the demand for new services statewide as called for in *Ligas* implementation, it will be quite difficult to expect providers to continue expansion or to attract new community providers with such low rates.
- The *Ligas* budget also includes \$446 thousand in FY12 and \$1.9 million in FY13 for contractual agreements called for in the Implementation Plan. To date, other than agreements with PAS agencies, there have not been any specific contracts executed or implemented for *Ligas* implementation. Contracts are called for in the areas of Outreach, Transition Planning and a Family Support liaison. Over the next six months, the Monitor will work closely with DDD to make sure these contracts are in place and fully operational.
- An extraordinarily long reimbursement cycle for reimbursement only compounds the challenge of operating with low rates and, at the same time,

asking the provider community to step forward and borrow even more in order to serve more people. The Monitor has received reports from many providers that reimbursement payments typically can take from seven to nine months. Even those who qualify for the “expedited payment” often report as much as 60 days or more for reimbursement payment. Over the next year, the Monitor will review this issue carefully to determine its degree of impact with compliance with the Decree.

## **Class Member List(s)**

The Decree requires the defendants to maintain a statewide database in which all Class Members are enrolled.<sup>9</sup> Defendants are also required to promptly revise the class member database and waiting list data.<sup>10</sup>

The Implementation Plan describes the process for the development and maintenance of a class member list that will be accessible to the Monitor and Class Counsel. Intervenors' counsel will have access to the class list as provided in the Implementation Plan. DDD will use its PUNS database to maintain a list of Waiting List class members. The Plan also calls for DDD to review the adequacy of the PUNS database.

Upon recommendation by the Monitor and agreement of the parties and intervenors, the defendants have developed and maintained two class member lists.

First, there is now a list of class members pursuant to ¶2 (a) of the Decree, 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. As of September 12, 2012 there were 697 class members in this category. The defendants maintain a list that contains, at a minimum: the names of individuals; the documentation to verify their written affirmative request; date of birth; social security number and; the name of the facility in which they live. Development of this list has been challenging and has required numerous modifications. Due to many various factors, including data entry errors, difficult transcription, interpretations of hand-written forms, undated or unsigned applications as well as numerous name discrepancies, initial lists contained many inaccuracies. The most recent list has been reviewed and re-

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<sup>9</sup> ¶8 June 15, 2011 Consent Decree at Page 8.

<sup>10</sup> ¶9 June 15, 2011 Consent Decree at Page 9.

reviewed and appears to be consistent with the requirements. Of particular concern has been ensuring that none of those listed as Objectors are not included on the list, unless there is a more current affirmative written statement that the individual and/or guardian has changed their mind and has since requested services in a community-based setting. A senior staff member within the DDD has been assigned to maintain this list and inform the Monitor of any particular updates and concerns. As a result of the events above, the quality and veracity of this list has continued to improve.

Second, there is a list of class members pursuant to ¶2 (b) of the Decree 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. These individuals are known as Waiting List Class Members. As of September 12, 2012, there were 10,894 class members in this category. This list is also maintained as a subset of the overall waiting list (Commonly known as the PUNS list) for services.

Development and refinement of this list has also proven to be quite challenging. Utilization of this initial list revealed that much of the class member information was outdated and/or inaccurate. A large number of addresses were incorrect and some individuals had moved out of state. Contact information was often inaccurate or outdated. Out of the initial 1330 individuals selected from this list to be funded for services, more than 350 individuals could not even be located. Some individuals on the initial list are now deceased. In more than 100 other instances, after individuals were contacted, it was determined that they no longer needed or wanted home and community-based services or services in a community-based setting.

As soon as these inaccuracies were discovered, DDD took immediate action to address these problems. The PAS agencies have the primary responsibility to update the information on the waiting list. Communications were sent to each

PAS agency with clear instructions on updating data on the waiting list and reminding them of their responsibility regarding individual updates. DDD assigned a key staff member as well as an additional professional staff member to work on this list as a high priority. These two staff are now in constant communications with PAS agency representatives to correct inaccurate data and update waiting list information. Budget allocation adjustments have also been made to ensure that payments to PAS agencies are reimbursed for PUNS entry and update activities on an expedited basis. These efforts thus far have been quite effective.

The Monitor is concerned about the often outdated and inaccurate data on the PUNS waiting list. This problem has already had a negative impact on compliance with another primary requirement of serving Waiting List class members. (See section on Transition for Class Members on Waiting List).

Over the next six months, the Monitor will continue to work closely with the DDD staff responsible for maintenance of the class member lists. As called for in the *Compliance Evaluation Standards*, the Monitor will then conduct a review of class member records using a random selection method of class members on both class member lists. Results of this review will be provided to the parties and intervenors.

As an overall note, the problems identified in the class member lists issue are also symptomatic of a more endemic issue within DDD – the lack of a comprehensive integrated data system. It will be important for DHS over the next several years to address this issue and develop a plan to address the overall need for a data system that is responsive and consistent with the ever-growing challenges within DDD and DHS. The Monitor recognizes that development of a comprehensive data system will require a significant initial investment of resources. The outcome of such an endeavor, however, would help ensure effectively coordinated services for class members and others.



## **Transition Service Plans**

The Decree requires the defendants to develop transition plans for all class members who are selected to be served pursuant to the Decree. Transition plans shall describe all services required, how they will be developed and obtained and a timetable for transition.<sup>11</sup> Transition plans will be developed by a Qualified Professional in conjunction with the class member and guardian and others, as appropriate.<sup>12</sup>

The process for transition planning will include the class member's personal vision, preferences, strengths, and needs in home, community and work and shall reflect the value of supporting relationships, productive work, participation in community life and personal decision making.<sup>13</sup> Services and supports will be integrated into the community and consistent with choices of class members and guardians. Transition plans shall not be limited by the current availability of services but be within the confines of the waiver and State Plan.<sup>14</sup> Transition plans for class members who are determined to be in crisis will be developed.<sup>15</sup>

The Implementation Plan calls for a phase-in process for the completion of a transition service plan for each class member seeking services in a community-based setting. The Plan outlines an 18-month long process that includes a pilot trial period, re-evaluation and state-wide implementation by July 1, 2013. This process ensures coordination required between PAS/ISC agencies and class members.<sup>16</sup>

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<sup>11</sup> ¶11 June 15, 2011 Consent Decree at Page 9.

<sup>12</sup> ¶12 June 15, 2011 Consent Decree at Page 9.

<sup>13</sup> ¶13 June 15, 2011 Consent Decree at Page 9 & 10.

<sup>14</sup> ¶14 June 15, 2011 Consent Decree at Page 10.

<sup>15</sup> ¶21.(b) June 15, 2011 Consent Decree at Page 12.

<sup>16</sup> Ligas Implementation Plan, 12/15/11, Section VI, Page 15

The defendants have begun to implement the transition planning process consistent with what is described in the Implementation Plan. These activities include the following:

- DDD developed Transition Service Plan documents through a process of receiving broad input from the parties, class members and families, PAS agencies and other key stakeholders. These documents include a Transition Plan format and accompanying instructions for class members moving from their homes or ICFs/DD to CILA and a more abbreviated form for class members seeking community-based services in crisis situations. On June 26, 2012, DDD facilitated a conference call of all PAS agencies, who will be responsible for completion of the Transition Service Plans, to discuss the proposed plan and receive final input. Once input was received, documented and modifications were made, the forms and instructional guidelines were finalized in July 2012.
- The finalized guidelines for the Transition Service Plans were also posted on the DDD Website. (*Ligas* website page)
- Two of the PAS of agencies who had volunteered to participate in the pilot evaluation process were selected. These PAS agencies selected to participate in the pilot are Developmental Disability Services of Metro East and Suburban Access, Inc.
- Following an initial conference call, both of the selected pilot PAS agencies and their program staff participated in a half-day training on August 23, 2012. The Monitor participated in this training activity.
- Each of the pilot agencies then selected a sampling of class members living at home and living in ICFs/DD who would participate in the sample. The total sampling size is 141 individuals. The period for completing the pilot and evaluating its results will continue through December 2012. Monthly conference calls with the two pilot PAS agencies will be conducted by DDD with the Monitor's participation to review progress and implementation challenges throughout the pilot period.
- After reviewing the results of the pilot activities, DDD will make necessary changes to the forms and processes in the beginning of 2013.
- By May 31, 2013, DDD will provide training to all 18 PAS agencies and begin statewide implementation of the new Transition Service Plan by July 1, 2013.

With regard to the transition planning process for class members in crisis, the defendants took a slightly different approach. DDD drafted modifications to the existing Crisis Funding Request and developed the *Crisis Transition Plan and Funding Request*. (Final Draft 7/25/12) This form and format, along with detailed instructions, were posted on the DDD website and disseminated to all PAS agencies for input. These documents were finalized and were required to be utilized by all PAS agencies statewide beginning September 14, 2012. Since this crisis transition planning form is a relatively minor adaptation to an existing form, a pilot process was not considered necessary.

The Monitor is generally pleased with the progress the defendants have made toward the development of a Transition Service Plan. 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 takes time to evolve. As these Transition Service Plans are evaluated, needed modifications will be completed and training and retraining will be implemented. Another component of this process will be the training of PAS agencies and others on effective person-centered planning. The *Ligas Implementation Plan* calls for a consultant to be identified to work with the DDD Bureau of Transition Services during the first two years of the Decree to review transition plans and train PAS agencies and providers on their development.<sup>17</sup> To date, this consultant has not been identified or hired. This consultant should be hired as soon as possible to begin work in coordination with the transition planning development schedule. Over the next year, the Monitor will carefully review the further transition planning process and report to the parties on the progress and challenges identified.

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<sup>17</sup> *Ligas Implementation Plan*, Section X, at page 21

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

The Decree requires all class members in ICFs/DD to transition to community services or community-based settings consistent with their transition plans if, at the time of transition, the class members request placement in a Community-Based Setting as confirmed and documented in accordance with the Decree.<sup>18</sup>

- One third of class members in this category will transition by 12/15/2013. The number of class members to transition during this period will be determined by June 15, 2013.
- Two thirds of class members in this category will transition by 12/15/2015. The number of class members to transition during this period will be determined by June 15, 2015.
- All class members in this category will transition by 6/15/2017. The total number of class members to transition from ICFs/DD will be determined by June 15, 2017.

The Implementation Plan calls for the identification and referral of these class members to PAS/ISC agencies for assistance in transition to community-based settings. The number of people identified for transition from ICFs/DD is expected to change, pursuant to the results of the outreach process described below.

PAS/ISC agencies will monitor the adjustment and resolve issues as they are identified.<sup>19</sup>

It is unknown exactly how many class members in this category will be identified on June 15, 2013. Of the number of class members identified on that date, one-third are required to be served by December 15, 2013. As reported in the Class Member List section, there were 697 class members in ICFs/DD as of September 12, 2012. As of that same date, 153 class members in this category have received

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<sup>18</sup> ¶17 June 15, 2011 Consent Decree at Page 10.

<sup>19</sup> Ligas Implementation Plan, 12/15/11, Section V, Page 14 -15

funding for community-based services or services in a community-based setting. Of the 153 who have received funding, at least 113 of these class members have actually started community-based services and billing for these services has been verified. On September 7, 2012, DDD sent requests to PAS agencies for monthly updates for 528 class members to determine the status of choice and selection of community services providers and projected transition dates. The overwhelming majority (97%) of class members who have transitioned have requested and received funding for Community Integrating Living Arrangements, (CILA) and the remainder of the class members (3%) have requested and received funding for home-based services (HBS) and have returned to their family home.

It should be noted that, to date, 19 individuals living in ICFs/DD who were contacted to receive transition supports to community services have since changed their minds and chosen to stay living in the ICF/DD. In each of these instances the individual's choices were respected and they were removed from the class member list.

A large number of class members who were living in ICFs/DD (61) who have moved services in a community-based setting did so as a result of a voluntary downsizing or closure agreement. There are expected to be at least 200 additional individuals who will be identified over the next year who are living in ICFs/DD now and will need to move due to voluntary downsizing or closure agreements. It will be imperative for the defendants to ensure that these individuals are provided with the opportunity to review an array of options so they can make an informed decision about where and how they want to receive services and supports. The Monitor has discussed this with the parties and DDD staff and will be working closely with the defendants in tracking how choices are being facilitated for individuals who are affected by implementation of voluntary downsizing and closure plans.

## **Crisis Services**

The Decree requires the defendants to serve Class members who meet the crisis criteria described in ¶21 (a) of the Decree and who request community services or placement in a community-based setting expeditiously.<sup>20</sup> Services and/or placement will be provided in a manner consistent with the transition plan.

The Implementation Plan calls for the PAS/ISC agencies to continue to submit requests for services from individuals in crisis situations. DDD will ensure that class members are served expeditiously.<sup>21</sup> The Monitor established the standard, 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.<sup>22</sup>

As mentioned in the introductory section, on May 1, 2012, the Monitor notified the defendants and class counsel of non-compliance in that crisis services were not being provided expeditiously as called for in paragraph 21(c) of the Decree. After a sampling review of the crisis services for class members from June 2011 to April 2012, the Monitor found a large percentage of class members who were not served for weeks and, in some instances, months, who needed services immediately. The Monitor recommended that the defendants develop a plan to address these issues. The defendants acknowledged the problem and immediately developed a draft corrective action plan and reviewed the plan with the Monitor. This draft plan was then presented to the parties and discussed at the June 21, 2012 parties' meeting. Following the meeting, class counsel provided written comments to the defendants on June 28, 2012 on the corrective action for crisis services. The defendants, in conjunction with the Monitor have since modified this plan and have moved forward with many of the action steps. The DDD Deputy Director for Community

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<sup>20</sup> ¶21.(C) June 15, 2011 Consent Decree at Page 12.

<sup>21</sup> Ligas Implementation Plan, 12/15/11, Section VIII, at Page 19

<sup>22</sup> Compliance Evaluation Standards, July 17, 2012 at Page 14

Services has been assigned the lead responsibility for overseeing implementation of the crisis corrective action plan.

Some of the key action steps in the Crisis Service Request Action Plan include the following:

- DDD has developed an internal quality assurance process and checklist for management staff and Network Coordinators to individually evaluate each crisis request packet to ensure timeliness and completion.
- The internal database has been modified to ensure accuracy of entities.
- Network staff have been provided additional training in the areas of crisis data entry and processing crisis requests.
- Network Coordinators have now been assigned authorization to issue Pre-Award Letters in order to expedite processing of these letters.
- Training will be conducted in October 2012 for DDD Network staff and PAS agencies about submitting complete and accurate crisis funding requests, and being fully prepared when presenting requests to the Review Committee.
- The frequency for internal DDD informal review committee meetings has been increased to reduce the lag time in approval.
- Rate setting unit staff have been instructed to give high priority to crisis requests which will be specifically labeled as high priority. Distribution of award letters will also be streamlined and conveyed electronically.
- A management report will be designed for improved overall internal monitoring of crisis requests. The first management report will be produced in the first week of January 2013.

Since the Crisis Corrective Action Plan has been implemented, the Monitor has reviewed the crisis requests from June 15, 2012 through September 7, 2012.

There have been 70 crisis service requests during that period. The defendants provided a status report to the Monitor showing the activities and outcomes of each one of these requests. The results of this review show significant progress, even for those requests processed prior to implementation of the corrective action plan. In most instances, protective and/or emergency services were in place in a

matter of days and not weeks, although some of the requests have taken longer than the 24-72 hour established standard.

The defendants should be commended for acknowledging the extent and seriousness of the problem and responding with the requisite level of urgency which, to date, has demonstrated early positive outcomes.

As mentioned in the Transition Service Plan section above, the defendants have developed and are now implementing the *Crisis Transition Plan and Funding Request* form. Utilization of this form as prescribed should result in a more effective and uniform manner in processing crisis request.

Historically, the defendants process approximately 300 to 350 crisis requests per year. Hopefully, as more individuals on the waiting list are served, this large demand for crisis requests will decrease. In the meantime, the Monitor will continue to closely evaluate the implementation of the corrective action plan and communicate the results to the parties. As called for in the *Compliance Evaluation Standards*, the Monitor will conduct a 100% document review of all class members served in crisis and 5% random sampling of direct communication with class members or their families to evaluate the response of the defendants and outcomes.



## Transition for Class Members on Waiting List

The Decree requires Class members described in ¶2.b of the Decree will transition to community-based services. These class members are referred to in the Decree as "Waiting List Class Members."<sup>23</sup> Class members described in ¶2.b and ¶22 (a) and ¶22 (b) will transition in accordance with the following schedule:

- Community-based services or placement in a community-based setting for 1,000 Waiting List class members will begin by June 15, 2013.
- Community-based services or placement in a community-based setting for an additional 500 Waiting List class members will begin by June 15, 2014.
- Community-based services or placement in a community-based setting for an additional 500 Waiting List class members will begin by June 15, 2015.
- Community-based services or placement in a community-based setting for an additional 500 Waiting List class members will begin by June 15, 2016.
- Community-based services or placement in a community-based setting for an additional 500 Waiting List class members will begin 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>24</sup>

The Implementation Plan incorporates the criteria for prioritization for selection of class members who are on the waiting list to receive funding for community-based services or services in a community-based setting. Within each category, selections will be made based on the length of time on the waiting list database.<sup>25</sup>

As reported in the Class Member List section above, the PUNS list shows 10,894 individuals who qualify as Waiting List class members. In order to implement a

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<sup>23</sup> ¶22.(c) June 15, 2011 Consent Decree at Page 13.

<sup>24</sup> ¶23.(c) June 15, 2011 Consent Decree at Page 13.

<sup>25</sup> Ligas Implementation Plan, 12/15/11, Section VII, Page 17-19

systematic process for selections of class members to effectuate services for the initial 1,000 individuals by June 15, 2013, the defendants engaged in several selection events. (Commonly referred to as “PUNS pulls”) The first selection event identified 800 individuals believed to be class members occurred in February 2012. After an initial screening process, 65 individuals were removed from this list and 735 letters were sent to the class member and/or guardian and their respective PAS agencies indicating that funding for community-based services or services in a community-based setting would be available upon application. The second selection event occurred in June 2012, which identified an additional 626 individuals and, after initial screening 22 individuals were removed from the list, resulting in 604 application letters being sent to the class members and respective PAS agencies. A third selection event is occurring presently and 1,500 individuals believed to be class members are being selected. Each of the selection events have chosen people in accordance within the criteria for prioritization as listed in the *Ligas Implementation Plan*.

As reported in the Class Member List section above, this selection process exposed significant shortfalls in the reliability of the PUNS list data. For example, from the initial selection of 800 individuals, 120 individuals were determined as unable to locate, 109 individuals have since refused services, 24 individuals have moved out of state, 17 individuals were found to be ineligible for HCBS services, 17 individuals were located in settings rendering them ineligible to be class members and 10 individuals are now deceased. These calculations alone result in nearly 300 individuals out of 800 (or 37%) who, if PUNS data were accurate would not have been considered class members. It should be noted that the initial selection of class members, generally, include many of those who have been waiting for services the longest. Thus some of the data for these individuals is more than six years old, contributing, in part, to the high level of inaccuracy.

DDD recognized the degree of inaccuracies and took immediate action to address the problem. Additional staff have been assigned to assist PAS agencies in updating PUNS data and, in a number of instances, have helped the PAS agencies directly in locating individuals or information about individuals through research and various database inquiries. This process has been successful but is arduous and produces results slowly.

Despite the gross inaccuracies of the PUNS list for the initial selections, there has been significant movement over the past six months in an effort to comply with the requirements. Movement toward the provision of services for those found eligible is as follows:

- As of September 1, 2012, services have been initiated for 135 class members.
- An additional 30 class members have received finding awards and services are about to begin soon.
- Packets for another 73 individuals have been completed to DHS for funding approval.
- 348 individuals are in the process of receiving Level II and Level III screening by PAS agencies and requests are being processed.
- Initial contact has been made with an additional 114 individuals who have confirmed that they have requested services.

In summary, if all of the above individuals who are being processed for services actually begin services by June 15, 2013, (An extraordinarily optimistic scenario) this comes to a total of only 700 class members, well short of the 1,000 class members as required in the Decree.

Meeting this requirement can only be possible if at least 300 more class members are served who are being selected for the current selection event involving 1,500 names from the PUNS list. Even if the letters to the class members from this selection event are sent as early as mid October 2012, it would be unrealistic to expect actual services to begin for many of these individuals by June 15, 2013.

The Monitor is gravely concerned about the likelihood of full compliance with this requirement in the Decree. To address this area of possible non-compliance, the Monitor suggests that the defendants take some additional steps toward further progress.

- First, some additional staffing assistance should be assigned to provide the necessary support to manage and conduct follow-up activities for the next large selection event. Reviewing PUNS data, working with the PAS agencies and identifying barriers during this process is an individually-driven and labor intensive process that requires an “all hands on deck” approach.
- Secondly, DDD should develop its own technical assistance arm for PAS agencies to teach, train and monitor the updating and entry of PUNS list information and processing of applications for services. The responsiveness of the PAS agencies throughout this process has varied greatly. Effort will be needed to ensure consistency and uniformity statewide.
- Third, DDD should identify areas where processing of service applications has moved slowly and develop administrative remedies where necessary. For example, it has been reported that processing the applications for Medicaid eligibility for some class members has taken several months, even where individuals already qualify for Supplemental Security Income (SSI) which indicates a strong likelihood for Medicaid eligibility. DDD or DHS could assist in the process of expediting the application process, thus moving applications forward more quickly.
- Finally, DDD could poll community service providers in every region to determine existing service options and opportunities that could be shared with PAS agencies to make individual choices more effective.

To assist in compliance with this requirement of the Decree, the Monitor suggests a special dedicated meeting in early January 2013 with the defendants and class counsel to provide a comprehensive update on progress at that point and identify and address any barriers to compliance.

## Outreach

The Decree requires the defendants to maintain a fair and accessible process by which individuals or their guardians can affirmatively request services and maintain records of those requests.<sup>26</sup>

The Implementation Plan outlines numerous activities designed to identify individuals throughout the state who are or will be in need of home and community based services and services in a community based setting. These activities include training and information sessions as well as the development and distribution of written materials to broad based audiences.

For potential class members living in ICFs/DD, the Plan provides a detailed description and requirements for the development of a Request for Proposals (RFP) to secure the services of an outside contractor(s) to contact all potential class members and determine and document an informed decision on whether they are requesting services in a community-based setting.

The defendants engaged in numerous activities to comply with the Outreach requirements of the Decree and activities described in the *Ligas Implementation Plan*. At the initial parties' meeting, it was agreed by the parties and memorialized by the Monitor that for those individuals who live in ICF/DD settings, they are considered a class member if they have completed a PASS Form 1238 or its predecessor, DHMDD Form1243, or DD PAS 10 form, or the Request form disseminated through plaintiffs' counsel, and checked the box that they choose Home and Community Based Services.

The Defendants, and in many instances, in conjunction with the Monitor, engaged in activities to inform stakeholders as well as the community at large about the

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<sup>26</sup> ¶25 June 15, 2011 Consent Decree at Page 14

requirements of the Decree and how services can be sought and received by qualified class members. Some of these activities include the following:

- DDD and the Monitor has have been conducting training activities for each of the 18 PAS agencies on the requirements of the Decree and Implementation Plan and, in particular, their role in facilitating choice for class members.
- DDD has developed a *Ligas* website<sup>27</sup> that includes a full and downloadable description of the requirements of the Decree, updates on documents and activities related to the Decree and contact information for parties interested in more information. This website is updated on a regular basis.
- DDD maintains a consumer-friendly PAS agency locator function on the DDD website whereby families can locate their PAS agency by simply entering their county or zip code.
- DDD has also structured the 1-888-DDPANS toll free number so that families can be directed to the *Ligas* inquiry staff support.

With regard to outreach to persons living in ICFs/DD, the defendants, with input from representatives from class counsel, intervenors counsel and the Monitor, developed a *Ligas* Outreach Request for Proposals (RFP) (Reference #22028606). The RFP was released to the public for solicitation on September 13, 2012 and proposals are due to DHS no later than October 9, 2012. This RFP is designed to secure the services of an independent contractor to 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 or services in a community-based setting or continue to receive services in an ICF/DD.

The Monitor is pleased that the outreach RFP has been released and looks forward to the selection of a contractor so work on this important endeavor can begin. At this juncture, the timetable for work by the contractor is six months behind schedule.

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<sup>27</sup> <http://www.dhs.state.il.us/page.aspx?item=40989>

## **Implementation Plan**

The Decree requires that the defendants finalize the Implementation Plan, with input from the parties and intervenors.<sup>28</sup> The Implementation Plan must be filed with the Court by December 15, 2011. The Implementation Plan shall be updated and amended at least annually.<sup>29</sup>

The *Ligas Implementation Plan* was negotiated by the parties and intervenors and filed with the Court by the defendants on December 15, 2011. There was joint agreement by all parties, the Intervenors and the Monitor on the initial Implementation Plan. The Plan was ordered as a supplement to the Decree on February 15, 2012.

The defendants have utilized the *Ligas Implementation Plan* as their blueprint for activities designed to comply with the decree. At each scheduled parties' meeting, the defendants provide a verbal update of Plan activities and respond to questions from class counsel and counsel for the intervenors. There have also been significant inquiries from key stakeholders and members of the public at large about implementation activities.

December 15, 2012 marks the one year point since the *Ligas Implementation Plan* was filed with the Court. The Monitor recommends that the defendants resubmit a proposed amended Ligas Implementation Plan with necessary revisions at the next scheduled parties meeting for review and input. Following the input from the parties, intervenors and the Monitor, the defendants should file the updated plan to the Court, as required in the Decree.

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<sup>28</sup> ¶27 June 15, 2011 Consent Decree at Page 15.

<sup>29</sup> ¶28 June 15, 2011 Consent Decree at Page 15

## **Data Reports**

The Decree requires the defendants to provide 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 towards achieving compliance.<sup>30</sup> Not less than every six months, defendants shall provide data reports to the Monitor, class counsel and intervenors.

**Implementation Plan Activities** – The Implementation Plan calls for the submission of data reports.

The defendants provided a draft data report format to the parties, intervenors and Monitor and have received their input. Since then, the data reports have been resubmitted to the parties and intervenors with additional input and feedback. Most recently, on August 20, 2012 the defendants submitted the Data Reports to the parties, intervenors and Monitor with data included from the first six months and second six months.

The Data Reports include class member data regarding the class member list(s), services to class members in ICFs/DD, services to class members from the Waiting List, ICF/DD resident outreach, transition service plans, crisis services, voluntary ICF/DD closure and downsizing agreements, eligibility appeals and the *Ligas* budget. The Monitor finds the form and format for class member data to be acceptable. It will be increasingly important, however, to ensure that data with regarding budget expenditures and shortfalls, if any, are updated on a regular basis.

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<sup>30</sup> ¶ 33 of June 15, 2011 Consent Decree at page 18.



## **Services for Named Plaintiffs**

The Decree requires the defendants within sixty days to offer each of the Named Plaintiffs the opportunity to receive appropriate community-based services or services in a community-based setting.<sup>31</sup>

The defendants have complied with this requirement of the Decree. All five named plaintiffs were offered services in community based settings and have successfully transitioned to their new homes or received home-based services funded through the Illinois home and community-based waiver.

## **Dispute Resolution**

The Decree clarifies the rights of class members to appeal or seek administrative or judicial review pursuant to governing law through the existing fair hearing process. Class members may also avail themselves of any informal appeal process that currently exists.<sup>32</sup>

The Monitor reviewed the appeal data with the defendants in April 2012 and identified a number of problems with the appeal process. Scheduling of appeals hearings and obtaining written hearing determinations were taking an inordinately long time, in some instances as much as six months to a year. The appeals application process was often confusing to individuals and families and some families reported that they were not aware of their appeal rights.

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<sup>31</sup> ¶37 June 15, 2011 Consent Decree at Page 21

<sup>32</sup> ¶24 June 15, 2011 Consent Decree at Page 14

As a result of these problems, the defendants, with input from class counsel, developed and are implementing an appeals corrective action plan that includes the following activities and tasks:

- HFS has hired an additional three new Administrative Law Judges as hearing officers and one additional attorney to support the hearing process.
- The newly hired ALJ's, at the request of HFS, conducted site visits to several CILA settings to better understand community-based services for people with developmental disabilities.
- The application process was streamlined so that appeals come directly to DDD rather than the additional pass through with HFS.
- A draft to include modifications of the appeals rights form is being finalized.
- Appeals unit staff have been instructed in writing to give top priority to crisis appeals.
- Appeals unit staff are being trained to expedite informal appeals.
- An internal checklist has been drafted to provide effective and ongoing tracking of appeals.
- PAS agencies are being re-trained on preparing complete appeal requests.
- Weekly internal management reports will be generated to ensure internal reviews are scheduled on a timely basis.
- Management reports will be incorporated into the *Ligas* data reports.

The Monitor is confident that the above action steps will greatly alleviate many of the procedural problems with the appeals process. Over the next year, the Monitor will review appeals data with the defendants and provide the parties with findings and recommendations for improvement.

## Section 5 – Overall Comments

As shown throughout this report, compliance with the Decree requires a systematic and comprehensive approach by the defendants, coupled with an infusion of significant resources now and over the next nine years. The report also illustrates the complexity of the various requirements and how each requirement is inextricably intertwined with many of the other requirements. In drafting this report and in conducting monitoring activities, the Monitor found it somewhat challenging to maintain focus not only on the details of compliance, but also on the fundamental principles of the Decree – That class members will be afforded the opportunity for real choices about where and how services will be provided and - Resources will be made available to respect these choices. Keeping those principles in mind, the parties and intervenors can be pleased that at least 323 class members have received funding approval for community-based services who, in the opinion of the Monitor, would not have received this funding without the impetus of the Decree.<sup>33</sup> This “bottom line” should not be overlooked.

In addition to this measure of success, there are numerous structural, procedural and cultural changes that have taken place over the past 15 months. In many ways, implementation of compliance related activities has exposed significant flaws in the service delivery system for people with intellectual and developmental disabilities. Some of these flaws have been addressed and many, if not most, still linger. Some of the compliance concerns articulated in this report are not because of lack of effort of the defendants but rather due to longstanding systemic and resources problems, that have yet to be resolved.

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<sup>33</sup> This number includes 153 class members transitioning from ICFs/DD, 165 Waiting List class members and five named plaintiffs.

The Monitor will continue to work diligently with the parties and intervenors to address these problems until substantial compliance with all of the requirements becomes a reality.