**Ligas Class Member/Family Advisory Committee**

**Meeting Minutes**

**January 20, 2015**

Committee Member and Staff Attendees:

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
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| **First Name** | **Last Name** |
| Dave | Adden |
| Silvia | Campone |
| Jim | Eddings |
| Donna | Frownfelter |
| Toni | Howard |
| Lige | Howard |
| Missy  | Kichline |
| Joanne | Kunz |
| Stephanie | Leach |
| Troy | Markert |
| Elizabeth | Miller |
| Laura | Miller |
| Kendra | Moses |
| Kit | O’brien-Cota |
| Tony | Records |
| Mary | Spriggs-Ploessl |
| Ruthann | Sikora |
| John  | Whitcomb |

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Other Attendees:

Mary Dickter and Vicki Niswander.

The meeting began at 1:10 pm as a video conference from locations in the Harris Building, Springfield and the Clinton Building, Chicago. Due to technical issues, the telephone conference line was not available.

See attached meeting agenda.

The minutes from the October 15, 2014 meeting were accepted without comment or correction.

**INTRODUCTIONS**: Donna Frownfelter, chairperson, began by asking that attendees introduce themselves briefly. See attendance list above.

**LIGAS FAMILY ADOCATES UPDATE:** Toni Howard reported The Ligas Family Advocates (LFA) continue to connect with parents/guardians and self-advocates. She met many self-advocates at Speak Up, Speak Out Conference which was held in November 2014. For her, it was quite an eye-opening experience to watch these young adults advocate for themselves and to listen to their personal experiences and how they have managed to triumph and excel in spite of having various disabilities.

If any attendees belong to a parent group or just know of a group of parents with adult children who would be interested in discussing their options, the LFA advocates are available. They can contact either Missy or Toni directly.

She also mentioned the 3rd Annual FSN Informational Seminar that is scheduled for Thursday, March 26th, 2015 from 8:30 am to 3:30 pm in the Bethune Room at The Heritage Plaza Banquet Facility located at 1550 W 95th St in Chicago (across the street from Third Baptist Church). There will be various vendors on hand to discuss their products and/or services. Admission is free for families.  To get more information, the link is:  [Brochure/Registration Form](https://gallery.mailchimp.com/bcec73d19574f43e0b9ab00c1/files/RevisedFSN_Informational_Seminar_Brochure_1_1_.pdf). If anyone has questions or needs additional information, they can either email or call Toni at 815-277-7310. The event brochure is also attached.

Missy Kichline updated the committee on several topics concerning the Ligas Family Advocates LFA):

* LFA has recently completed a brochure;
* LFA has received a list of class members selected and found eligible for services.  Advocates will start contacting members as soon as possible;
* The LFA website will be reviewed by William Richard of IATP (Illinois Assistive Technology Project) for accessibility. The LFA website is: <http://ligasfamilyadvocateprogram.org/>;
* In November, Missy advised/assisted 21 self-advocates (27 total participants) in attending the Speak Up, Speak Out Conference in Springfield;
* She has been working with Lore Baker in supporting several individuals from the Edwardsville area in developing supportive housing options;
* She is also working with an individual and his family to secure Medicaid eligibility. It is important for families and individuals to seek out organizations that have experience and expertise when working with complex systems such as Medicaid or other health benefits for people with disabilities, particularly when involved in an appeal situation;
* She has participated in two transition fair events as a vendor and a speaker. There are transition fair events in February and March where she will participate as a vendor.

**CLASS COUNSEL UPDATE:** Laura Miller reported that the Division has been working hard with a small staff to achieve Ligas compliance, and shows a strong commitment to get people into the community.

DDD has met the numerical goals of the Consent Decree. She has also seen many, many positive transitions into CILA or onto HBS. There is a need to focus, though, on some compliance issues.

In September, the Court Monitor issued a report making no findings of non-compliance. In October, counsel for Plaintiffs sent Monitor letter asking for findings of non-compliance with respect to person-centered services, noting:

* failures to include PWD in planning process;
* failures to provide CILA to PWD with high medical or behavioral needs;
* failures to honor preference on CILA size and location;
* failure to honor preference for integrated day programming.

The Monitor convened meeting of plaintiffs and defendants to resolve issues, and Defendants agreed to address issues in the 2015 Implementation Plan (IP). Plaintiffs agreed that, if properly addressed in IP, there will be no need for finding of non-compliance.

Plaintiffs received a copy of the draft IP. It did satisfactorily address failure to include individuals in planning process. However, the other issues were not satisfactorily addressed. We sent a second letter to the Monitor asking him to facilitate changes to the IP and, if this is unsuccessful, find the defendants out of compliance with the Decree.

**DDD LIGAS UPDATE:** Jim Eddings, with the Division, stated that as of January 1, 2015, 2164 of the Ligas members pulled from PUNS were receiving services. The Ligas members who were residing in ICFs and are now receiving services total 945. The Division has already met the goal for June 2015 for placing Ligas members in services.

He also stated a revised Ligas Service Plan was sent out by the Division as Informational Bulletin DD.14.046, viewable at: <http://intranet.dhs.illinois.gov/onenet/page.aspx?item=75364>

**COURT MONITOR UPDATE:**  Tony Records provided a brief overview of his Third Annual Report. The parties are now negotiating changes in the 2015 Implementation Plan with particular focus on the transition planning process and community capacity. The parties are taking a closer look at why some class members who were selected for services are not yet being served. An update of this process will be provided at the next meeting. There is also serious concern about the budget situation for FY15 and possible cuts for FY 16.

**CEREBRAL PALSY AND TRANSITION PLANNING:** Silvia Campone offered her thoughts and experiences in obtaining services for her non-ambulatory son. “Service Providers tend to shy away when approached by potential clients that are non-ambulatory, along with a cognitive disability. Service Providers know that non-ambulatory clients are more expensive to provide care for. It is easier to hire aides and to provide housing for ambulatory clients since the cost is calculated in the service provider model. The budget for a non-ambulatory, cognitively impaired client is always in the "grey" area. Home-based services are seldomly an option for clients that need total care that are non- ambulatory. The home-based rate does not even cover respite care for half a month of services when 24-hour care is needed.  The rate of Home-based services should be raised for people that require care to allow that to be an option.

“Job coaches are hardly ever offered to non- ambulatory, cognitively challenged clients, thus this client often ends up in a "workshop" with minimum care, or stays home.

“Special Recreation Associations are a great source of providing care in a social setting.  However funding is restricted under CILA and Home Base budgets.  Special Recreation Associations are the true "hands on" organizations in a community setting that would be an invaluable tool as part of any overall care program.

“Finally, I suggest that special consideration be provided for clients that are non-ambulatory that are approached to receive CILA and Home-based services.  Agencies need to think outside the box and be opened to alternative solutions, along with a suitable budget.  Parents and clients need to have reasonable expectations, and need to provide realistic guidelines on the care that is required.  Caregivers for CILAs or Home Base need to be compensated differently than a caregiver that provides care for an ambulatory client.”

“Rocky” Kunz also shared her thoughts on service planning for individuals with cerebral palsy. See attachment.

**LIGAS AND NON-ACCESSIBLE CILAS:** Due to time restraints, this topic was not covered.

**LIGAS COMMITTEE “INFORMATIONAL WAREHOUSE:”** Missy Kichline originated the idea of gathering information obtained during the Ligas Member/Family Advisory Committee and make it accessible in one location. She will explore the option of using tools available from the Family Support Network.

**CQL VIDEO:** The Division’s outreach vendor, Council on Quality and Leadership (CQL), created a 12-minute video which discusses the various living options available to Ligas members. Technical difficulties prevented the sound from being heard at both video conference locations. The video may be viewed at: <http://intranet.dhs.illinois.gov/onenet/page.aspx?item=75298>

**NEXT MEETING:** The Committee agreed to meet next on Tuesday, April 21, 2015 from 1 to 3 pm. The meeting will be held again via video conference from the same rooms: Executive Video Conference Room in the Clinton Building, Chicago and the Secretary’s Conference Room in the Harris Building.

Contact Dave Adden with any questions or comments related to the Ligas Individual/Family Advisory Committee: daveadden@illinois.gov or (217) 524-0848.