DDS West Region Advisory Council May 20, 2016 **Minutes**

> Ella Grasso Center, 300 Armory Road, Stratford, CT 4:00pm

Present: Charles Bergamo, Lori Chiappiniello, Marina Derman, Fritz Gorst, Alison Jacobson, Gil Kellersman, Karen Simon, Arlene Steinfeld

Guest: Lauralyn Lewis (RAC South)

Citizens who signed in: JoAnn Campos, Alice Evans, Laura Gibson, Emilia Gilbert, Colleen McGill, Ana Tosado, Sandra Williams

Call to Order:

Meeting called to order at 4:11 pm

Approval of Minutes

There were no formal minutes from the last meeting to review (due to the absence of a quorum).

Introductions

Introductions took place as many of the members on the Regional Advisory Council are new.

Citizen Comment

One of the family members began to question members of the Council and where their respective family members are placed. Mr. Kellersman responded with information about his daughter. At which point, Mr. Bergamo requested that the citizen speak to members of the Council privately (after the meeting) to ask for such personal information. He stated that it was inappropriate for Council members to divulge private information that is HIPAA protection in an open meeting such as this.

Mr. Bergamo kindly mentioned to the meeting participants what the role of the Council is. A member of the public inquired as to how the members were chosen. Mr. Bergamo shared that the members are appointed by the Commissioner of the department. He also shared that anyone interested in participating in this group should contact the Commissioner's office.

Many family members of Ella Grasso residents were present at the meeting. Several of them expressed their frustration with the closing of the facility. Some of them were visibly distraught and some were very vocal about how upset they are with the decision to close the home of their family members.

One of the family members made a comment that "One size does not fit all" and what works for one individual may not necessarily work for another individual. The closure of EGC is very upsetting and these families are not happy.

Mr. Bergamo expressed his position as the Chairperson stating that the Advisory Council can be the voice for the family members in this matter. The Council can share the request that families have to be treated in a respectful manner. A member of the public requested information on mold which she states is present at the Lower Fairfield Center. She showed a picture and demanded follow up on this. She stated that she has made numerous requests to numerous departments and her requests are not responded to.

After the citizens commented, SR member shared a bit of history on how long the Advisory Council has been around and how important it is to become an active Advocate for consumers. She shared that she makes weekly visits to Hartford to advocate so that the voices of our constituency is heard. She stressed the importance of having more families become actively involved so that the message is loud and clear that our consumers need to be cared for. They are a very vulnerable population and most cannot speak for themselves so it is imperative for more and more people to participate on committees such as the Advisory Council. She shared information about how active the SR Council is and she hopes that the WR Council can continue to move ahead with getting the word out to more families. She reminded families about how bad our fiscal situation in Connecticut is and that families should contact their legislators so that their voices can be heard. She shared that if anyone would like to see what is going on they can tune to CT News Network as there are televised sessions for the public to view.

Fritz reminded families that DDS remains committed to work with families for a smooth transition and families are encouraged to contact the case manager to look at all of the available options for their family member. He explained that time is running out and that June 30th is around the corner and time is of the essence since funding for the 2016/17 fiscal year has not been provided for the Ella Grasso Center. There is no expectation that this will change.

A brief discussion of the oversight that is provided at the Intermediate Care Facilities (ICFs) occurred. An explanation of what occurs for licensing was also shared. Fritz explained that any issues or concerns that the families have brought up over any physical plant concerns would be looked into and resolved prior to any consumer moving.

Regional Director Update:

- A handout on the waivers was distributed. Fritz mentioned that Siobhan O'Neill can be invited to a future meeting if the Council requests it.
- Fritz shared information on **Senate Bill 294** which has new language on the Advisory Council and how DDS has to inform families annually of the Advisory Council.
- Senate Bill 1601 Section 23 was also briefly discussed. This bill explains how the DDS Commissioner will identify a plan to close Southbury Training School and Regional Centers. This report is due by December 2016.

- Stemming from this closure plan is the closure of Ella Grasso Center, Stratford. Due to the recent budget Fritz shared how he received notification of the closure and how the Ella Grasso Center and Meriden Center were chosen. The EGC is closing on June 30, 2016. The administrative offices will remain open until an alternative location for these offices is identified. Once the Center is completed vacated the property will go to the surplus list.
- Fritz explained that families impacted by the EGC closure would receive the same level of care that the receive at the EGC.

Advisory Council Information

Mr. Bergamo read the statute and shared a hard copy with the Advisory Council. The statute outlines the role of the Council, the criteria for the membership of the group. He also distributed information from the DDS website that members may find useful.

Mr. Bergamo is hoping that as the group continues to work together and identify issues and topics that they are interested in that subcommittees will form to further pursue focus areas. For example, if someone is interested in getting legislative information and sharing it with the group that would be helpful.

He sees the Council in its beginning stages which allows the group to structure themselves as they choose. The Council has several new members so the hope is that the group will becoming more actively involved.

Facebook Page

As stated at the last Advisory Council meeting, Mr. Bergamo hired someone to create a Facebook page for him. He sees this as a platform to begin lines of communication with families and a great place for resources to be shared. The page will focus on getting as much information out there as possible. He sees it as a source of valuable information.

There was a brief discussion on who will be monitoring the page for any issues that may arise (i.e. negative commentary, etc.). Mr. Bergamo stated that he would be the Administrator of the page and will take care of any issues that may come up.

An invitation to share email addresses with Mr. Bergamo was presented. Anyone that would like to become a "friend" on the Facebook page can send their information to Mr. Bergamo and he will send an invite to "like" the Facebook page.

The page will include events, family pictures (that are voluntarily shared), success stories, etc.

Final Comments

Mr. Bergamo will send an electronic invite to like the Facebook page to anyone that provides him with their email address.

There was a suggestion to have the next Advisory Council meeting on June 16^{th} . An email will be sent to members to determine the best available date for a June meeting to keep the momentum of the group going.

Meeting Adjourned

No further discussion and meeting was adjourned at approximately 6:03 pm.

Next Meeting

June 16, 2016 at 4:00 p.m. – Ella Grasso Center, 300 Armory Road, Stratford, CT

Respectfully submitted by:

Eunice B. Rivera

Eunice B. Rivera, Executive Secretary