

# Draft

## **FAMILY SUPPORT COUNCIL** **Monthly Meeting** **February 19, 2009**

**Date:** 2/19/2009

**Place:** Commission on the Deaf and Hearing Impaired

**Time:** 10:14am - 12:00pm

**Facilitator:** Karen

**Recorder:** Chris Sloss (Respectfully submitted 2/27/09)

**Attendees:** *Voting members* –Karen Zrenda (Parent), Terry Cote (DDS), Ann Gionet (DPH), Cindy Stramandinoli (Parent), Mike Selvaggi (Parent), Angela Spino (DD Council/Parent), Kathleen Bradley(DCF), Colleen Hayles (SDE) *Non-voting members* - April Dipollina (Parent/FSN), Eveleen McDonald (OPA), Tom Brooks (COC), Deborah Pagano (SICC), Moira O’Neill (OCA), (Mona Tremblay & Lisa Sheppard via conference call) *Guest* – Martin C. Zito (DDS) *Staff* – Chris Sloss

**Welcome and Introductions** - Meeting was brought to order by Karen Zrenda at 10:14 and introductions were made. A quorum of voting members is not present today. No votes will be taken.

**Acceptance of January Minutes** - The following requests were made.

- On the list of attendees it was requested that we list voting members, non-voting members and guests since some of the attendee’s are statutory members. Chris will make this change going forward.
- A request was made prior to the meeting that the wording in the minutes (with regard to the SDE document Before, During and After the PPT) be rearranged to more accurately reflect Colleen’s response to Mike’s request.
- No vote could be taken to accept the minutes since we do not have a quorum present. Will table the approval to our next meeting.

### **Citizens comments:**

Karen sent an e-mail to everyone to notify them that Representative Faith McMahon had passed away. A card was sent to the family on behalf of the council as she was a great supporter of our efforts on behalf of children with special needs. A suggestion was made to take up a collection and then give it to a family (in Faith’s honor) that has a child with special needs. If you are interested in making a contribution please contact April Dipollina.

April noted her concern about the council’s difficulty completing our business at each council meeting and noted her concern about the plans for the Legislative Meet & Greet.

Kathy B –The Information and Operations sub- committee established at the last council meeting (members are: Kathy, Mike, Molly, Angela, Sylvia, Laura, Chris & Sara Reed) has been trying to set a date for a meeting that can satisfy everyone’s needs. Kathy has two possible sites available in Wallingford to host a meeting. She will notify us once the details are in order so that

it can be posted. Reminder that this group was established at the last council meeting to focus on developing the protocol for minutes format, access to public information and records, other public agency responsibilities, and access to agency information as requested.

Kathy also wished to make a comment regarding the time she spends attending council activities. For the record, she does not take paid time by her agency to attend Council meetings.

Cindy asked who she could go to regarding her concerns about the council's current difficulty completing our business.

Mona asked if we could look into our legal obligations to allow the network coordinators to vote as parents.

### **FSC- Public Testimony**

Governor Rell has proposed the elimination of several Commissions we work very closely with as well as our own Family Support Council. The following suggestions were made:

- We attend and speak at the public hearings whenever possible
- Submit letters from our members urging the committee's to NOT support these eliminations. Bold that we are non- funded, bullet our accomplishments on a single page, mention the number of families we have reached through the networks. Highlight that all of the work is done through networking & advocacy. Mention how important our partnerships have been to our success and progress of the council (i.e. Katie Beckett)(See attached Outline of additional suggestions)
- Send Governor Rell a specific invitation to attend our Meet and Greet.
- Call your local legislator and share specifics about the work of the council. Ask for their support!

Moira has shared an outline of the bill summaries, committee membership lists and contact information. Thanks Moira!

Discussion ensued regarding the logic behind elimination of the council since we do not receive appropriations. Individually we can speak to any of the noted bills –but not as a council unless we have a special meeting. Karen can coordinate this meeting from Yale New haven Hospital since it needs to be held in a public place with a conference call-in option.

### **Legislative Meet and Greet:**

March 5<sup>th</sup> 2009 from 9-10:30am at the LOB

We need to have a lot of families present, a focus and speakers. It was suggested that we have one consistent message at the Meet and Greet about why the FSC is important. Please e-mail Karen any suggestions or letters as to how the FSC and Network has helped families, saved the state money, etc. We need parents to speak out on the importance of the FSC at this breakfast. We need parents from our own council as well as other parents to speak (or send letters.) Also, a crucial part of the breakfast is making contact with your legislators beforehand. Please reach out to your local representatives and invite them to attend the breakfast. Encourage other family members and colleagues to do the same and then seek out their legislators in the building and have a face to face visit with them before they leave!

Discussion ensued about the need for the subcommittee (which was approved by the council at the Dec. meeting) to organize the breakfast yet it was suggested that they do not have authority to make decisions about the theme of the breakfast and the activities that will occur there.

Suggested that we: (1) provide copies of previously approved statements, brochures, materials that will educate the legislators about the council. (2) ask folks to show up early & hold an emergency meeting at 8:45 to approve any new statements (3) individual people can speak about issues related to children with special health care needs (4) The theme of the breakfast is that the FSC facilitates the opportunity for people to come and speak to their legislators about the issues their family has experienced.

We agreed we will proceed with the meet & greet as planned.

We will host a special meeting soon so we can vote on our recommendations for legislative support. We can then include that information in the packet at the legislative meet and greet.

**Annual Report:** we will discuss in the special meeting.

**Agency , Subcommittee and Program updates:**

Colleen wanted to let folks know that there will be some training for parent advocates and certification provided by SDE regarding the rollout of the new learning disability guidelines. (There have been some changes in terms of eligibility.) Details are yet to be finalized, so once it becomes available she will e-mail Chris to forward to the group. She believes the date will be March 17<sup>th</sup>. They will be offering one session during the day from 10am-12 noon at SERC in Middletown and another in the evening (time not certain) at the same location.

Also, the next addition of the Bureau Bulletin is due to come out by the end of the week and they usually have a lot of information about what is happening currently in the state.

Mona wanted to let us know that the Aspergers PDD group is up and running for families in the NE corner. It is growing rapidly. Sara Reed will be speaking to the group on the 24<sup>th</sup> of this month. They also started a new morning support group in Willimantic and have a translator available through the CHDI DPH grant initiative. This will be a regular morning monthly meeting in addition to their regular support group that meets at the John Dempsey Center for children with all disabilities.

April sent out flyers about a few initiatives that provide front line services for families. This is an example of how the network facilitates and then shares with the council the needs of the families. If anyone wants more information please contact April directly. A new B-3 initiative got started in her area by a therapist at Lawrence and Memorial. They have an integrated B-3 playgroup that also involves siblings!

The FS subcommittee tabled what they had been working on in order to focus on families and the breakfast. During this meeting Mona suggested that perhaps her son's class could speak at the Meet and Greet. Having met prior to the budget release, their original suggested focus was "Do not cut" They also discussed the need for options noting that not all families need the same kind of services. So again the focus is: Don't cut, keep options open. They also briefly touched on the catastrophic relief fund. Since this subcommittee meeting our priorities have changed again. Our number one priority needs to be Save the Family Support Council.

Kathy wanted to remind us that if we have a child with special needs from B-6 years old that is experiencing any kind of difficulty in their daycare or early child care centers that the Early Childhood Consultation Partnership is available to make sure that those children are not suspended or expelled from those daycare centers. For contact information at ABH (Advanced Behavioral Health) Middletown CT e-mail Kathy Bradley. There are 20 statewide consultants who do this work so every region is covered. They also provide services in the Head Start programs. If you have children living in the New London, Groton, Norwich area you also have access to Building Blocks which is a grant for children who have identified mental health diagnosis. They will do a wrap around service for those families. Kathy can e-mail these flyers for distribution.

Ann will send copies of her flyers electronically. CT has a multi-cultural health care partnership. Four different focus groups have been scheduled for March where they want to dialogue with health and social service representatives from various state agencies and non profits about cultural competence and diversity training for employees.

Moira – The Office of the Child Advocate is primarily focusing on the proposed elimination of the Office of the Child Advocate. They did review the Governors budget and found that their really were not any substantial cuts to programs directly serving kids with special health care needs at this time.

Tom – The Commission on Children had a major forum on Children and The Recession. Materials and video clips pertaining to this are on their website. They tried to focus on the message that significant cuts now to programs are going to cost even more in the future. They were talking about result based accountability, prevention, testifying on the bill concerning the FSC technical changes and in that testimony they mentioned the legislation that would eliminate the FSC, they also testified on the catastrophic bill from representative Schofield that is not quite what they introduced last year.

**Adjournment of meeting** - Meeting adjourned at 12:00 as Chris shared the video presentation she prepared for the Legislative Meet & Greet. If anyone has photos they would like to add please e-mail them to Chris along with the photo release.