

Draft

FAMILY SUPPORT COUNCIL Monthly Meeting March 12, 2009

Date: 3/12/2009

Place: Commission on the Deaf and Hearing Impaired

Time: 10:14 am – 12:12 pm

Facilitator: Karen

Recorder: Chris Sloss (respectfully submitted 3/19)

Attendees: **Voting members** –Karen Zrenda (Parent), Terry Cote (DDS), Ann Gionet (DPH/Conference call), Karen Hlavac (Parent), Merva Jackson (Parent/AFCAMP on conference call) Joan Law (Parent on conference call), Laura Knapp (Parent via conference call), Robyn Trowbridge(Parent), Colleen Hayles (SDE) **Non-voting members** - Liza LeGrier (Citizens for quality sickle cell care), April Dipollina (Parent/FSN on conference call), Eveleen McDonald (OPA), Tom Brooks (COC), Deborah Pagano (SICC), Moira O'Neill (OCA), Mona Tremblay (Parent /FSN) Jen Carroll (Parent/Statewide coordinator FSN), Tesha Imperati (Parent/FSN), Alice Buttwell (Parent/FSN via conference call), Lisa Sheppard (Parent/FSN via conference call) , Tom Brooks (COC) Joy Liebeskind (CT Lifespan) **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 present today.

Acceptance of the January February, and Special Meeting minutes

- ❖ January minutes – Motion to accept the minutes with changes by Karen Hlavac, Seconded by Robyn Trowbridge, all in favor, none opposed. Motion passed.
- ❖ February minutes – Motion to accept the minutes by Robyn Trowbridge, Seconded by Karen Hlavac, all in favor, none opposed. Motion passed.
- ❖ March Special Meeting minutes – change requested by Joan to add a note recommending that the FSC be available to support DCF initiatives by making ourselves available to the legislators and agency for input around the changes and reorganization of DCF. We can direct our letters to The Select Committee On Children. Motion to accept the minutes as amended by Karen Hlavac, Seconded by Karen Zrenda, all in favor, none opposed, Merva, Ann, Terry & Colleen will abstain since they were not in attendance at this meeting.

Point of order - Karen Hlavac was able to clarify that we were referred back to our own By-laws regarding the voting of minutes. Our by-laws state in section 7 under Meetings that minutes will be prepared by a representative of the lead agency, distributed through the mail, and approved by the council at each meeting. So you can vote as long as you have read them.

Proposed schedule change of the FSC meetings: Chris will do an electronic survey asking for the best times and days members can attend a FSC meeting.

Legislation:

There will be a public hearing Monday March 16, 2009 9:30 am in Room 2B at the LOB that will address a few different bills:

1. HB 6375 An Act concerning Review and Termination of Certain Boards and Commissions. (The FSC, COC and CDHI are listed on this bill for elimination) We were encouraged to write or attend the meeting on Monday to voice our concerns about these proposed eliminations. When you get up to speak mention that you want to comment on all of these bills. Merva suggested that we make a statement explaining that the legislative hearing process is discouraging for families. Merva will draft a letter on behalf of the council sharing these concerns and share with the FSC so that anyone who attends can add this statement onto their testimony. A reminder that they do except written testimony. It can be mailed to General administration and election committee. You can look up the Co-chairs of the committee on the CT.Gov website.
2. S.B. 839 An Act Concerning Mergers and Consolidations of Various State Agencies
3. S.B. 840 An Act Concerning the Elimination of the Office of Consumer Counsel, The Office of the Healthcare Advocate, The Office of the Ombudsman for Property Rights and Certain Legislative Commissions. Moira offered to draft a sample letter. Motion to take a stand on Senate Bill 840 to support the Office of the Healthcare Advocate by Robyn Trowbridge, Seconded by Karen Hlavac, all in favor, none opposed. Motion passed.
4. H.B. 6152: An Act Established a Catastrophic Medical Expenses Pool – Jen encourages folks to keep an eye on this committee bill. This could be valuable source of funding for families who have excessive costs for their children with special healthcare needs. We as a council in the minutes of our special meeting agreed to support the concept of a catastrophic relief fund and would write a letter of support. (Jen will forward Vicki Veltri's e-mail summary of the language in this bill to Chris to forward to FSC members.) It seems unlikely this bill will pass this session but it is important to keep it alive by writing to legislative leaders so that they know that people are interested in it. Vicki encouraged people to keep it in the conversation on universal Health care.

Co- Chair elections:

Merva declined her prior nomination due to contractual obligations with AFCAMP. Karen H commented that she appreciates her nomination however feels she should decline because she does not feel as though she has the depth of knowledge of Karen Z. given her long history with the FSC. Karen H. recommends that someone shadow Karen Z before taking on the co-chair role. Robyn agreed with Karen H that there would be a fairly dramatic interruption if Karen Z. stepped down at this time. Discussion ensued regarding keeping co-chairs on while shadowing (1) co-chair designee at a time.

Current by-laws indicate we are to elect 1 co-chair and 1 co-chair designee at this time.
(At the January meeting Terry nominated Laura so Laura withdrew her nomination)

Election:

Terry nominated Karen Z as co-chair and Karen H as co-chair designee assuming Laura would continue in her co-chair role until July at which point we would have another election. Robyn seconded that nomination.

Other nominations? Asked (three times) do we have any other nominations for co-chair & co-chair designee? Nominations for co-chairs closed. All in favor, none opposed. We then voted on the slate of nominations. All in favor of support of this slate. None opposed. No abstentions.

Public comment

Question: Can a non-voting member be a co-chair? Regional coordinators are not eligible to be officers of the council because under the statute they are not members of the council, they are only members through the by-laws. They would need to be eligible under the statute in order to be eligible as an officer.

Mona - Asked for clarification as to whether family support network coordinators could be appointed members prior to our next scheduled meeting regarding this. Her understanding is that unless there is a conflict of something that would directly benefit an individual coordinator there should be a legal way for parent regional coordinators to vote. Tom suggested that we speak to the Office of State Ethics for a new opinion on this issue because some of the particulars have changed.

Karen suggested that we will try to get clarification from the Ethics Commission as to whether or not FSN coordinators can become appointed members of this council. (Council can send a letter to the Ethics Commission asking them for guidance) Tom agrees this should be expedited and that we set up a meeting with the Ethics Committee if possible Tom would volunteer to join council leaders in going to meet with them.

Karen made a motion that we write a letter on behalf of the council and set up a time to meet with the Ethics Commission to get an immediate clarification on this issue. Karen Z. made a motion Karen H. seconded, all in favor, none opposed. Motion passed.

By-laws under Section 4 Quorum– A quorum for a meeting is one-third of the total appointed members. Action at meetings shall require a majority vote of those present and voting, *but no vote of the council shall be taken unless two-thirds of the voting membership present are parent representatives on the council.* This is why we need to increase appointed parent membership. Do we have any proposals on how we want to change the wording on this? Membership committee was asked to take a look at this and Tom prepared some recommendations. Suggested that the membership committee reconvene and at a later date make a full presentation to the council. The recommended changes from Rod at DDS some time ago state a simple majority of the appointed members of the council shall constitute a quorum.

Legislative Meet and Greet re-cap

It was a successful event. It was exciting to see all the families there and have a room full of our supporters. Julian's team was spectacular! The class and staff went around to their individual legislators who commented how critical it is in this economic climate to have faces to remind them of the issues when they are voting.

Jen Carroll, Tesha & Karen H went to many legislators as well and dropped off packets. Karen Z went with Karen S (testifying parent) and Joan Law also went around and distributed packets to

several legislators.. Robyn spoke to Kathy Abercrombie. April spoke to more legislators this year than she has in the past. We spoke to more legislators this year than we ever have.

FSN and Agency Updates:

Joy mentioned a new commission is looking to be formed called a quality homecare council. They would oversee and require training for PCA's, etc.(Joy will e-mail to the council) This is up for public hearing on the 17th.

FSN is doing another statewide forum Thursday May 7th on "What is a Medical Home?" The next Together We Will Conference will be April 2 at the Holiday Inn in Waterbury. Information about the conference is on the SERC website. Grace Curtis *Stand Up And Be Counted* is scheduled for March 23rd. There are two adults on the spectrum that will be speaking, both are authors. Tesha is extremely busy with phone calls PPT's, and home visits. Will be meeting with the sib shop at Yale soon. Mona extremely busy with IEP, PPT support and many expulsion reports. Support groups are running very well and getting great attendance. Lisa also very busy.

SDE -Helping Kids Succeed in School Workshop. March 23rd. There will be 2 other sessions March 17th (9:30 am & 5:00 pm held at SERC) the audience will be geared for advocates and other service providers so they are aware of forthcoming changes. Another Bureau bulletin came out which has a helpful link titled "Meet the Bureau of Special Ed that identifies all the current consultants in the bureau and what area's they focus on. This is a good resource.

Commission On Children (Tom) wanted to Thank the council for support and suggested that if you have not yet signed up for e-mail newsletter please consider it because their activities are listed in the newsletter.

Citizens for Quality Sickle Cell - (Liza) – has monthly support groups on Friday evening. They will be doing trach counseling and free community testing to see if they have the gene that can be passed on. The next meeting will be April 11th at the Bushnell center for performing arts from 12-2pm.

Motion to adjourn by Karen Hlavac and Seconded by Robyn Trowbridge. Motion passed.