

Draft Minutes

FAMILY SUPPORT COUNCIL

Annual Meeting

July 9, 2009

Place: Commission on Children

Time: 10:15am-12:00pm

Facilitator: Karen Zrenda

Recorder: Chris Sloss (Respectfully submitted 7/15/09)

Attendees: *Voting members* – Karen Zrenda (Parent – Co-Chair), Terry Walsh (Parent), Karen Havlac (Parent – co-chair designee) Laura Knapp (Parent call-in), Joan Law (Parent) Kathy Reddington (DDS) , Moira O’Neill (OCA) , Robyn Trowbridge (Parent), Ann Gionet (DPH – Call-In), Laura Knapp (Parent – Co-Chair-Call –In), Merva Jackson (Parent) *Non-voting members* - Jennifer Carroll (FSN/Parent), , April Dipollina (FSN/Parent –Call In), Karen DuPlessis (Child Dev. Infoline), Eveleen McDonald (OPA), Maureen Smith (OHCA), Alice Buttwell (FSN/Parent Call –In), Lisa Sheppard (FSN/Parent Call-In), Deb Pagano (SICC/Call-In)) *Guest* - Susan Hammond (Parent), *Staff* -Chris Sloss

Welcome and Introductions - Meeting was brought to order by Karen Zrenda at 10:15am. Introductions were made. A quorum of voting members is present today.

Karen Zrenda made a motion to add the following items to the agenda:

Family Support Council appointments

Annual retreat

Correspondence

CT Council on Developmental Disabilities grant update.

Kathy Reddington seconded the motion, all in favor, none against, no abstentions.

Review of Minutes – Suggestion: Please use first and last names in the minutes for clarity and consistency. Terry Walsh made a motion to accept the minutes, seconded by Moira O’Neill, all in favor, none against, Kathy Reddington abstained, minutes accepted.

Public comment – Jennifer Carroll shared that she and Tesha Imperati met Susan Hammond (our guest) at Service Coordination training with B-3. Jennifer thanked Susan for her interest in being a participant of the council. Susan is from Oakville, CT. It would be wonderful to have another representative from that part of the state.

Co-Chair vote –Our by-laws state that we need to post our slate with the notice of the annual meeting. Since we ran out of time at the last meeting this was overlooked and the slate therefore not posted. We reviewed the slate that was proposed at the March 12, 2009 meeting. The original slate listed Karen Zrenda and Karen Hlavac as co-chairs. Per the by-laws any council member

shall have the right to make nominations for any office from the floor at the annual meeting. There were no proposed changes to the original slate other than the addition of Robyn Trowbridge as secretary. Karen Zrenda made a motion to accept the proposed slate of officers, seconded by Moira O'Neill, all in favor, none against. No abstentions. This slate was accepted and will be attached to the minutes for the next meeting.

Legislative updates:

As a follow up to the councils decision at last months FSC meeting to draft a letter to our state representatives and senators voicing our concerns over the proposed budget cuts, Karen Zrenda circulated a copy of the letter which was drafted in cooperation with Katie Magoon (intern with the OCA) who assisted Karen in drafting the letter, along with input from Eveleen McDonald. A copy of the letter will be distributed to all.

Moira O'Neill shared that Katie Magoon is a pediatric nurse practitioner masters student at Yale School of nursing who is doing a clinical rotation through the office of the Child Advocate. She has been assigned to the FSC with her chief project being to review all of the legislative activities of this past session and the budget outcome. Katie will present a summary at our annual retreat to help guide us in developing our initiatives for the coming year. She will also be available to help draft any letters the council sends out. She will meet with each of the agency contacts to get a sense of the issues going on within there agencies. Katie will also meet with the network coordinators to get a sense of what the issues are on a grassroots level.

Kathy Reddington shared that the state agencies have been given an allocation for July (in lieu of not having a state budget) so they have some money to offer primarily for health & safety programs that are essential.

Jennifer Carroll reported that the network has been meeting regularly with Kathryn Dupree and recently Kathy Reddington at DDS. With regard to family support, specifically the case management cuts due to retirement, DDS is waiting for final approval of ten new case managers and one new case management supervisor. Six of those case managers will be housed (2) in each of three regions to be the contact team for families who no longer have case management. The network will work closely with the families in the regions as the parents have such difficulty with the DDS paperwork.

One of the proposed budget limitations included in the Governors most recent budget proposal was to remove from the proposed list of cuts some of the supports that families would still have access to (though they wouldn't have case managers) for example respite services, IFS grants, along with behavioral supports etc. The IFS grants and respite centers apparently are removed from the list of cuts. Families of graduates were able to receive grants up to \$5000 to get them through until there is a budget to help support them this summer. Kathy Reddington commented that some private agencies have (out of the goodness of their hearts) decided to start them sooner without funding. We were reminded that it is important to keep the lines of communication going to the legislators and the Governor (since there is no budget right now.) Families need to share their concerns about what programs need to stay in the budget and what might we be able to live without. They need this information. If they stop hearing from us they will think that our

issues are resolved.

Joan Law and Merva Jackson suggested that we find a way to acknowledge the generosity of the private providers. It was suggested that we look to the CCPA (CT Private Providers Association) for a list of private providers so we can recognize their contributions.

Action step – Robyn Trowbridge suggested that we establish an annual recognition program for private providers. Those who volunteered to help draft a proposal of parameters of how and when we can recognize a few private providers and present to the council at the retreat are: Robyn Trowbridge, Chris Sloss, Karen Zrenda, April Dipollina, Joan Law and Jennifer Carroll.

Merva Jackson shared that there is a pending lawsuit being raised regarding Voluntary Services. If you are aware of a family that has applied and been denied Voluntary Services because of the budget issue please contact Martha Stone at the Center for Children’s Advocacy (or Merva Jackson at AFCAMP)

FSC appointments - Karen Zrenda circulated a copy of the letter we received from the Office of State Ethics in response to our question as to whether or not FS network members can seek appointments. The letter explains in response to our questions, a staff member of the network may be appointed as a voting member of the council. The network team has been given a list of which legislators have vacancies at this time if any coordinators wish to become appointed members.

Karen Zrenda also shared another letter from the Attorney General’s office that states designees of the Office of the Child Advocate can be voting members. Moira O’Neill expanded on this sharing that The OCA was established after the FSC. So depending upon when an agency became a member that office may or may not have been included in the written statute regarding who could vote. In the OCA’s statute it specifies that the Child Advocate has the authority to designate a staff member to be his/her agent thereby giving voting authority to its representatives.

FSN updates:

Jennifer Carroll: Shared that the network support groups typically slow down during the summer. Announcements : Their proposal was selected for continued work on the DPH Title V Children with Special Healthcare Needs Outreach Program. They are also continuing with DDS funding. They are working with a variety of partnering agencies such as Infoline, P&A, CPAC, and other advocates to put together some regional forums with the networks this fall and will continue to report on this as details unfold.

Laura Knapp shared that there is new contact information for the northern region of the state for Title V services. CT Children’s Medical Center, Specialty Support Center, 877-835-5768 or via e-mail at arodriguez02@ccmckids.org There are several care coordinators at CCMC so you will be directed to the Special Kids Support Center admin staff who will direct the call.

Lisa Sheppard has been very busy with families specifically regarding the DDS and DCF

Voluntary Services issues. She has had some serious issues she has had to work through with families surrounding behavioral issues. Lisa has also been working with Stamford Regional Medical through transition because they have the staff which has been great.

April Dipollina announced that her camp will be a reality. It will run August 10th-14th (orientation will be the 9th) Currently 19 kids have registered. April helped another family advocate to help their daughter get her high school graduate services over the summer. Her daughter was connected to a private provider who said they would support her daughter even though the funding is not there yet. A question was raised if slots were still open? April suggested that questions be directed to Jen Hickey – jhickey@ehearcnlc.org via the website The ARC of New London County, or by PH# 860-889-4435

Lastly April has been working collaboratively with organizations in her area. There is an integrated playgroup that is in its second session after being awarded a recent grant. She knows another parent who has a foundation with funds that is looking to start a similar playgroup in another region of the SouthEast. Lastly she has another parent who has gotten very active on the regional advisory council so it has been nice to see parents stepping up and getting involved in policy, advocacy and direct services for families.

Alice Buttwell been working with individual families. Families will be getting together in August with the hope of starting a new sib shop in New Milford. Lastly Alice has been partnering with Waterbury CT Legal Services to help families.

Merva Jackson's team has been focusing on education, outreach and a few legislative items. They have been educating families on the budget cuts and trying to get key community organizations (such as churches) to become more involved. Many of the families Merva's group deals with have expressed concern because they did not feel they had adequate services prior to the budget cuts. There is an even greater crisis now that the services have become so limited. They have done some collaboration with the COC on some of their initiatives this past month. PPT's have kept their group overwhelmed. They are collaborating with several legal organizations as well as having dialogue with OP&A to try to get some of the issues addressed.

Agency Updates

Moira O'Neill announced that OCA had a case of a child who had been admitted to be covered by the money follows the person program. This was exciting news because it was the first time a child was included in the program. The program covers people who have been institutionalized for more than six months. It covers for 1 year and then they go on a waiver thereafter. Limitations: the facility has to be covered by Medicaid.

Merva Jackson's group formed a committee to look at the 2010 Long Term Care Plan for CT (see prior e-mail). She will share feedback with Karen Zrenda so the FSC can provide feedback on this so the children we work with are included in this long term plan. Anyone else who can read over the plan and provide feedback please contact Karen Zrenda to discuss.

Ann Gionet : DPH will be sponsoring along with the DD Council (4) special education training sessions. Information to follow. There will be 25 slots to anyone who is interested. It will be

focusing on the tool kit Angela Spino has presented before. (IDEA) Materials are available on the DD Council website.

Retreat

Based on our survey results our annual retreat will take place Thursday, September 10, 2009. We have not decided on a location or facilitator as of yet. We should try to make it a productive day and look to make some changes, expand our council, fill our membership slots etc. Moira O'Neill (and Katie), Karen Hlavac, Laura Knapp and those on the award committee offered to help with the planning of the retreat. Start thinking about what we can do to make this a great day.

Eveleen McDonald offered to talk to Gretchen about reviewing Roberts Rules in a few meetings or as a training session where we can open it up to other councils.

Correspondence

Jennifer Carroll voiced her concern about not having a listserv. The thing she misses about the listserv is that there were people who paid attention who may not have been able to attend council meetings, but responded when they had an idea or skill set when a situation arose. Jen currently has 2 families in such dire need – both in Hartford, single moms with multiple kids, little supports, incredible special healthcare needs, no vehicle about to be evicted etc. Jen often worries that she may not have enough information. Many of us have come across families in similar situations. Jen is hoping that at some point we can have the listserv back as a way to share information. Karen proposed that we open up the listserv through the network. Karen offered to monitor it, Joan Law offered and Lisa Sheppard also offered to oversee the listserv.

CT Council on Developmental Disabilities grant update:

The grant that has funded Chris Sloss' position can be carried until the end of 2009. Please try to think of funding sources and share your idea's with Karen Zrenda.

Motion to adjourn the meeting by Merva Jackson, seconded by Robyn Trowbridge, all in favor, meeting adjourned at 12:00 Noon.