

Draft

FAMILY SUPPORT COUNCIL
Special Meeting
November 12, 2009

Date: 11/12/2009

Place: DDS East Hartford with a conference call in option

Time: 10:05 a.m. - 12:01 p.m.

Facilitators: Karen Hlavac and Robyn Trowbridge

Recorder: Chris Sloss (Respectfully submitted 11/16/09)

Voting members: –Karen Hlavac (Parent Co-Chair), Robyn Trowbridge (Parent co-Chair), Laura Knapp (Parent), Kathy Bradley (DCF), Kathy Reddington (DDS), Joan Law (Parent), Lisa Sheppard (Parent), Jen Carroll (Parent), Angela Klonoski (Parent) Karen Zrenda (Parent), Moira O’Neill (OCA), Ann Gionet (DPH/Call-In), Mona Tremblay (Parent/Call In) Alice Buttwell (Parent/Call- In)

Other: Terry Cote, April Dipollina (FSN/Call In), Deb Pagano (SICC/ Call-In), Eveleen McDonald (OPA), Kareena DuPlesis (Infoline), Virginia Pertillar (Citizens for Quality SC), Tesha Imperati (FSN/Call in), Chris Sloss (Staff)

Call to Order: Meeting called to order by Karen Hlavac at 10:05

Public Comment: None

Approval of October Minutes: Motion to accept the October minutes with changes by K. Zrenda seconded by M. O’Neill All in Favor, None opposed, Motion carried.

Corrections:

FSN SW – Program is not about non-profit but rather age outs in DDS who are significantly impaired whose parents believe there is a need for more maintenance services (OT/PT) and a different kind of program for that specific population.

Under Officer Election and Agency Updates, K. Bradley is listed as SDE. It should be DCF.

Page 2 paragraph regarding letter of support for C.O.C. amended to include the following:

There was discussion about the fiscal crisis we are in and the difficulties many state agencies are dealing with relative to their budget cuts.

Page 1 second paragraph under legislative updates, medically necessary needs spelling correction. Spelling error page 2 first paragraph, NY state is already “brining” should be bringing.

Clarification on the * next to peoples names: Could not clarify, so request to remove the *.

Annual Recognition Award: R.Trowbridge shared some follow up to our idea about creating a recognition award that will acknowledge the unique efforts and powerful impact some private providers and/or individuals have made for families in CT. This award will be showcased at the Legislative Breakfast. Reviewed criteria to receive award i.e.impact they had on families or individuals, does it create lasting opportunities, does it create collaborative/partnership opportunities. It was suggested that we do this regionally and that C. Sloss send out nomination forms one last time looking for other possible regional recipients. We are looking for community effort as opposed to state agencies.

Listserv Update – The list serve has been turned back on so we can start using it. This listserv will be used as an exchange between families and providers to brainstorm issue's, share resources etc. There will be parameters to post so the system is not abused. K. Zrenda will be sending out the guidelines and parameters of expectations shortly. This is an invitation only listserv, so if you know someone who has an interest in joining you must email K. Zrenda with their name and e-mail so she can invite them. J. Carroll proposed setting up regional and statewide groups within the listserv as folks might only be interested in local information as opposed to statewide. K. Zrenda will create a “Key” to designate subjects so readers can determine quickly if they need to read or not. We will continue to keep our separate list of council members and attendees to send all e-mail pertaining to official council business only.

MOTION: M. O’Neill made a motion to have K. Zrenda continue as the moderator, seconded by L. Sheppard all in favor, none against. Motion passed.

General Business : anything we discussed in the past or something we would like to revisit in the future would fall under this agenda item.

Annual report- K. Zrenda gave overview of how it was generated in the past. Decide on legislative agenda, the items we want to highlight as important issues to families in the state. Divvy up sections reviewing issues and make recommendations. There is a basic template to follow. Would like to request a small summary of changes this year from each agency to add to the report. T. Cote has been instrumental in putting this together the last 16 years and has offered to assist with this again as will K. Zrenda. C. Sloss offered to print and put together packets

M. O’Neill suggests doing an online survey of families to find out what is working for them in these tough economic times and what is not. What is the urgent need? How are people coping? Prepare a list for legislators of what cannot be ignored. Gather information by January so it can go into the annual report. M. O’neill and J. Carroll offered to create the survey. Need to get approval from DDS and get it out by Dec. Others who offered to assist are L. Sheppard, K. Zrenda, K. Bradley, L. Knapp, K. Reddington offered to assist with IRB survey approval.

K. Reddington suggests covering the new insurance law coverage relative to autism as this is a positive outcome for families. OHCA may have data to substantiate our findings relative to this issue. We will ask Maureen Smith if she would be willing to consult on this project. K. Reddington offered to help with summary aspect.

C. Sloss will call the LOB for possible dates in March for our Legislative Breakfast.

DDS case management comment: Families need to understand that they need to contact them (DDS). There are still services available, but there won't be unless they make the call.

Election of a secretary: R. Trowbridge has been acting as secretary and co-chair. It was suggested that we look for nominations from the floor to take over the secretary position. (See By laws for details regarding nominations and duties of secretary.) Chris will continue to take minutes but this will need to be approved by the secretary. One suggestion was that J. Carroll take over this role. She will take this under consideration. We will open this up for discussion and take nominations at next months meeting. Please come prepared with possible nominations. **MOTION:** K. Zrenda made a motion that we will elect a secretary at next months meeting and L. Knapp seconded it. Unanimous approval.

FSN Updates:

J. Carroll shared that she has allocated funds from her budget to hire C. Sloss to continue doing 5 hours of website work a week.

ASRC event was tremendous. J. Carroll met a gentleman who is a distributor for a video phone company, ACN Digital Phone Service, that is great for kids with sensory issues. Please view the following link for further details <https://www.myacn.com/digital/> Contact J. Carroll for further inquiries.

Southwest/A. Dipollina –Some of the kids in the developmental playgroups will be transitioning out of B-3 in February. A. Dipollina in partnership with CPAC will put together a workshop for these families. Targeting December for this workshop. A. Dipollina has begun to look for grants for camp. Lastly, she is directly telling parents what services are available and who to call regarding the case management issue.

Northeast/M. Tremblay – is working with a lot of new families and many right before they age out of B-3 or shortly thereafter. Doing many presentations. Going to many PPT's for young groups (3-5 yr olds.)

Southwest/L. Sheppard – Redirecting families who lost case management with DDS to other available supports. Parents voicing fear of losing services because of the budget cuts. L. Sheppard is finding that district special ed. directors are calling her for assistance

in finding services and supports for families. Districts open to forming support group with social workers and Lisa.

Northwest/A. Buttwell – attended DDS resource fair in Torrington, networked with parents and providers. DDS has regional specific family support respite center programs that can help families with respite issues. Running and attending various support group meetings, and providing outreach.

Southcentral/ T. Imperati – Continuing the service coordination training and working with providers on how to provide outreach to families. Biggest issue currently revolves around children not previously identified. The schools are using the new state guidelines. The SRBI is not identifying children right away. T. Imperati is getting a lot of Questions so she is meeting with C. Hayles at SDE to gather more information for families. Sib Shop support group is going well. Busy with PPT's, home visits, and helping families through B-3 transition to schools.

Agency Updates:

DCF- K. Bradley will share more next month.

OPA – E. McDonald asked if we had anyone attending the Poverty Task Force and Sustinet meetings as these are the two priorities in the state politically. T. Imperati & K. Bradley are trying to stay involved on the Poverty Task Force. The next meeting for Children in the Recession is scheduled for Thursday November 19th. E. McDonald suggested this might be a good topic for Legislative Breakfast. She is wondering if any parents working with the network folks might be interested in attending Sustinet meetings.

DDS – K. Reddington commented that some money was rescinded by the Governor. (Limited) that had to do with cash. They lost 3 million in account for salaries. Agencies are working with governors office on next years budget, specifically how we can reduce the budget because revenues are much lower than expected. Regarding autism they are looking at three autism waivers specifically at up to 250 individuals who are being served under these waivers and those already receiving existing services so it's a revenue enhancement. They are looking at DMHAS population. There are 11 folks they are trying to move out of hospital type setting into the community.

OCA – M. O'Neill -Tomorrow at 10 am the OCA is holding a press conference to begin the celebration of the 10 year anniversary of the READ (Reading Education Assistance Dogs) program. Great program strictly run by volunteers through 20 libraries around the state. There are 4-5 schools that have child specific programs.

DPH- A. Gionet – They were having fiduciary issues around the family support grant through CHDI. They were able to piece together the funding for the first year which is good news. They have not yet identified funding for yrs 2 or 3. They have also been working on the medical home training curriculum and if there is anyone that wants to

participate you can contact A. Gionet and she will let you know about any upcoming meetings.

Citizens for Quality Sickle Cell Care – V. Pertillar is looking for a PT case manager 15 hrs a week 860-223-7222 for the New Britain area. She is the only staff person at this time with the Sickle Cell Care organization, so if you know of anyone who may be interested please share this information. She has recruited 5 new board members and is currently working on emergency room protocol guidelines. They just completed a 3 day hemoglobin training where they had 22 participants and recently did their second phase of the Online TV program titled “Face Sickle Cell.”

Motion to adjourn the meeting by J. Law, seconded by L. Knapp Unanimous approval
Meeting adjourned 12:01 p.m.