

Draft

November 18, 2008
 Chauncey Pavilion, Gaylord Hospital, Wallingford, CT

In Attendance: Kathy Bradley, Thomas Brooks Alice Buttwell, Jennifer Carroll, Terry Cote, April Dipollina, Karen Hlvac, Tesha Imperati, Joan Law, Joy Liebeskind, Eveleen McDonald, Moira O'Neill, Deborah Pagano, Michael Selvaggi, Mona Tremblay, Robyn Trowbridge, Karen Zrenda

1. Minutes – Mike S. complained about receiving minutes and agenda late. Motion to accept minutes with changes: #5 add commissioners to be notified in regards to separate 800 number for Voluntary Services (DCF and DDS). Tom said there has been recent legislation regarding the availability of minutes. Mike S was referring to 1-225. Discussion whether FSC is a public agency or a Council. No other member requested clarification. Some discussion in re. Jen Carol moved to accept the minutes. Kathy from DCF seconded the motion. Mike S abstained, all approved.
2. The meeting is being recorded by Mike S. Some members took objection to the meeting being recorded and expressed concern that they weren't extended the courtesy of being informed prior to recording. All were duly notified that the meeting was being recorded and moved forward.
3. Quorum – 1/3 of appointed members – today 7 are present and 71% are parents. Question in re who can vote. Currently some agency members are not by statute allowed to be represented on the council by agency so their representatives cannot vote. (Current proposal to change statute to allow agency heads to be represented.) 5 parents present today make a quorum.
4. Priorities and Action Steps identified from the FSC Retreat. Karen Z. and Moira O. reviewed and made suggestions for action steps.
 - a) Kathy from DCF will attempt to draft a letter to address #10 transportation with DOT. Karen suggested gathering transportation information from all members to create a fact sheet. Terry C. noted that DDS is working on info for their website and new service is NU-Ride that will assist with finding carpooling, etc. DDS will have a link on their website. For now can Google Nu-Ride. Karen will send out to FSC list serve. Joan Law talked about service for elderly. Joy L. mentioned limitations on transportation available to people with disabilities but family members may not be able to also go for the ride and there are some flexibilities with timing. Mona T. said disability advocacy collaborative is making transportation a high priority so may want to talk with Stan to assist. Joy will contact Stan to talk about support for advocating for transportation. So send Karen Z. ideas/information and she will put together a fact sheet.
 - b) Eveleen M. asked about #24...wants to know if we can get on this priority as far as increasing Spanish-speaking membership. Joan L said should

- combine that priority with the membership committee priorities. Joan said membership committee is addressing and attempting to create a strategy to increase and diversify membership. Eveleen said highest growing population in CT is Asian so needs to be looked at. Need a goal to increase or work towards diversity. Membership committee is addressing this. So Karen is adding #29 Address Membership, Diversity and Council Structure – action step are assigned to Membership Committee
- c) Mona addressed #7 in re disparity of autism pilot across the state. Not an equitable distribution of the program. She knows parents who are writing legislators about this. Individuals do not have services and cannot access the pilot. People are anxious and we are multi-years into process so she expects families will have a louder voice.
 - d) Mike S talked about the burden/expenses of parent participation on the FSC. He notes that statute indicates reimbursement and would like to see that occur. Also he notes that meeting in day time hours means loss of income and would like to move meetings to night time hours. Karen said she will survey the membership to see if members are willing/able to attend meetings in later hours. There was also discussion in re available child care for meetings.
 - e) Karen L. said she agrees with diversity efforts but also need to cultivate the individuals and the political appointers to be mindful of the need. She also said that all ideas have merit but she is worried about current economic climate. She proposes focusing things that are not associated with high costs that will further ideas and continue to chip away at others.
 - f) Robin said she met with Chris Donovan who referenced the movie Nimo – he said remember the scene where all trapped in net and going in different directions and were only able to move forward when figured out how to swim together. That is the mantra going forward. Also must be cost conscious. She feels that the focus this year will be to stay afloat,
 - g) April said that before writing letters to agencies (as outlined in some action steps) wait to hear from Family Support subcommittee, that is part of their strategy.
 - h) Joy L said Medicaid Managed Care meeting made it clear that autism pilot is only a pilot... that is why it is not available across the state. It has to be fully developed and proven to work and systems developed with data showing they work...Mona expressed frustration about responding to people in her corner of the state who have no pilot or access to services. Jen C. said that she sits on advisory council for autism bureau and noted the restrictions in the piloting of programs and collection of data. She also noted that there is another pilot coming in Hartford area and suggested the FSC write a letter to encourage expansion of towns in that area. She also knows there is intention and support from OPM to develop a waiver for young adults with autism. She thinks having families and the council write letters and continue to encourage attention to where the need is not being met. Strongest influence will come from the families not being served. Robin said Chris Donovan said it will all be about recovering

resources so waivers will be huge but he also noted the power of local efforts, don't forget to do you local efforts. Eveleen said because there is no funding, the more legislators see activities in the community, like the FSN, the better. She is proud of the FSN. Legislators would be really impressed with the FSC working a little more on cultivating the community which would reflect on the diversity of the community and she would be willing from P&A to assist with the Networks and build networks with existing community-based groups. Goes back to #24 to ensure materials are in Spanish and also any language that exists in the community. Hospitals have language interpreters. She is glad to look into it. A statement that doesn't just say in Spanish but aimed at accommodating any language. The more work we do in communities the more languages will come up...need access to interpreters and ability to let people know where they can access languages. Karen said change wording of #24 to "Non-English-speaking families."

- i) Robin said make a commitment to maximize community efforts in eastern CT.
- j) Joan L said, in re #7, instead of saying expand the pilot say promote the success of the pilot...promote the data. Mona said the problem with the way the expansion is slated to go is far corners of state will not be included for years. Terry C. noted that if it becomes a waiver cannot restrict geographically. So action step to #7 will be: mobilize families to write letters to legislators; Mona will put together talking points to help with that.
- k) Joan on #1, two projects in CT: Bridgeport and New Britain got grants from DCF to do Wrap-around Milwaukee training, trainings from FAVOR. All pieces equal family support. So in terms of #1 recognize it is happening around the state and try to get to the table in each of those towns. Prevention of kids 9-13 from ending up in Juvenile Justice System. Joan attends Bridgeport. Other members attend other meetings. Discussion in re who can be available to attend different meetings.
- l) Mike S said in talking about resources and efficiencies. Said an agency came to his house spending hours and days filling out forms, etc and assessing service needs and nothing ever happened. Kids need services and not people going to people's house killing time. Need to focus on efficiency which is a theme here. Money is being wasted foolishly. He doesn't know what the FSC can do. Terry C. explained how DDS does family need assessments and how they are used to both determine needs of individuals to serve immediately and also to know needs in the future when resources become available.
- m) Karen said it was 11:30 and we had to move on

5. December Meeting – 12/11/08

- a) Discussion in re what type of meeting we will have. Originally planned as usual meeting with some focus. Recent e-mail from Merva indicated a hearing-type gathering with commissioners and legislators. Robin

recalled that the last meeting discussion was about being ready for a good and focused meeting. Joan L said membership committee wants to get fully organized before having a big public hearing and shining light on FSC. Terry said getting organized first and then changing legislative breakfast to a more forum-type event. Concerns about ability to prepare families in short period of time. Moira recalled discussion about two different events, first, having a meeting with commissioner members.....

- b) Mona talked about Family Support committee identifying other partners to the process. Ideas of who else might come to the table. Also, with letter drafted by Chris, trying to make sure each member understands what each agency does so a resource book could be developed for assisting with family support activities...how to help families work with each agency. This doesn't cost anything, time well-spent.
 - c) Consensus that December is too early for major forum event.
 - d) Jen wondered if too late to invite the ombudsman from the agencies. Don't need big presentation but just introduce folks. The focus would be on building partnerships, not making complaints.
 - e) April said the Family Support Committee decided need to know who is on the FSC and who else should be invited. Hoped to identify and invite all to the council and ask each agency for a brief bulleted sheet -- example included in handouts today -- that outlines what agency does. Then move into putting together some kind of consolidated resource. Help start organizing family supports. Want to know if the newly identified folks should be included as members in the statute. She proposed the committee reconvene and put out some suggestions over the listserve.
 - f) December meeting should be regular meeting possibly at P&A, Eveleen will confirm. Agenda will be to focus on membership issues. Also some February event planning.
 - g) February big event planners – Terry C., Tisha, Robin, April, Joan, Jen C, Merva, Karen Z.
 - h) Joy L suggested reserving the Concourse to do display FSC/FSN stuff – Karen will contact Office of Legislative Management. Moira will develop a proposal for organizing a wall display and/or information and resource table event.
6. Karen thanked everyone for their participation today and for making it a productive meeting.
 7. Great feedback on the Medical Home Forum the FSN put on. Many providers and agency staff who work with families attended.
 8. Eveleen shared a new document...How Can P&A Help You. Family Support
 9. Commission on Children releasing annual social health of children index.
 10. April motioned to adjourn, Mona seconded. No objections.