

FAMILY SUPPORT COUNCIL

July 11th, 2008

Note Taker: Chris Sloss

Attendees: Karen Zrenda, Jennifer Carroll, Eveleen McDonald, Liza LeGrier, Karen Hlavac, Joan Law, Angela Spino, Sylvia Gafford-Alexander, Tom Brooks, Laura Knapp, Terry Cote, Rod O'Connor, Mona Tremblay, Chris Sloss, Lisa Sheppard, Deborah Pagano, Molly Cole, Alice Buttwell

Introductions & approval of minutes: Chris Sloss, new staff to the council, was introduced and briefly shared her background with the group. I am looking forward to working with you all!

Membership Committee Report: - A small work group had been organized to look at membership to the council and the meeting quickly moved to include by-laws. The group invited Rod O'Connor from DDS to meet with them prior to the Council meeting to review the by-laws and perhaps get some suggestions on changing them. This has become priority #1. Rod had some good ideas for tightening up the bylaws. He will go back to the legal team at DDS and ask about making the FSN people voting members to the council and whether there would be any ethical issues associated with that. The work group will meet again to create a revised draft of the by-laws (the goal being to have the by-laws completed prior to the retreat) and then begin to work on membership.

Retreat: - Typically at the retreat we look at our accomplishments of the year and identify what our priorities are for the coming year. We look at the legislative priorities or agendas that we want to support. We get input from the network coordinators of what they have heard as themes for family's priorities. It was suggested that we look at the responsibilities of the by-laws and look at those requirements in the statute and make sure we are doing what we are charged to do.

Four locations were to be considered for the retreat 1) Gaylord Hospital Pavilion, 2) LOB 3) the location in Branford and 4) Camp Harkness. The dates proposed are Wednesday Aug 20th from 9:30-2:30 or the backup date would be Friday the 22nd same time. Karen Z will send e-mail with further details.

What we need to gather for the retreat:

Regional coordinators are asked to bring list of themes and things they have been running up against in their areas

We want each of the State Agencies to bring their agency priorities and legislative priorities to be considered.

Our question to them is how best is it to speak with the commissioner from your agency?

Whatever we hear from families as a concern be sure to bring.

Speaker at the retreat: No one suggested a specific guest speaker for the event but Joan had suggested discussing the role of the various agencies, their presence at our meetings, and what we as the family support council expect of them and their participation. Someone suggested it would be nice to discuss with them a particular area of concern that we are hearing a lot about and doing some form of reverse reporting from state agency representatives (ie. can you get the answer to this & get back to us by X) Again, it seems we are wanting to define/tighten up the roles/expectations of our members. It was mentioned that we really need to have the state agency reps at the retreat. Eveleen asked if we could create a list of questions to submit before the retreat so those state agencies can come prepared or we could have a follow up meeting with the commissioners at the LOB

Guest for future meetings – No one identified at this time – prefer to focus on agency business for the time being.

Agency and FSN updates –

Jen - In response to a request Joan has made a few times, the network now does a monthly report that they submit to Jen and she combines it into a quarterly report that tracks the number of families they are working with. Jen can bring to the retreat the most recent quarterly. The list of boards & councils that they all belong to is a full page so everyone is working hard to support the agencies that support the council. Regions are having regular support group meetings themselves as well as attending support groups run by other folks so they partner, network and share information, they are working with Birth to Three doing care coordination training, they just started the 2nd year of the DPH medical Home grant, partnering with CHDI and that seems to be going well in their aspect of the work. Their role in this project is family education and working with child health & development and their role of training pediatricians and developing those professional partnerships.

Mona -. A lot of people going to the CPAC picnic. Mona has met with a local clinician who is beginning to see kids in counseling who have high functioning autism. This woman has offered to foot the bill for an August Family Fun day. Mona solicited Angela's support for a case she has been working on involving a Brooklyn teenage boy with aspergers accused of murder. Judge wants him tried as an adult. This year Mona is dealing with a high number of families who are having problems with their PPT's not coming back accurate, expectations not being met (in addition to them being done so late) Her medical home membership is up & some of the local family resource agencies in the school district will be meeting with her & her care coordination group to see what they can do to be more responsive to families.

Alice mentioned that the support group she's been working with in Waterbury has really started to lose members. There has not been a good presence at the meetings so she will attend a back to school rally to try to network and provide outreach & hopefully get more involved with the people that work in the school system. Alice would like to put another support group in Torrington. They have great support in New Milford & are working with a New Milford Youth

agency. They alternate support group and educational information meetings and are also working with the youth director to start a SIBshop.

Lisa Sheppard – Similar to Mona, she has been dealing with a large number of PPT mistakes. Lisa is working with 4 support groups. 2 are not active right now because it is summer but B-3 group is becoming pretty solid and will start having speakers in September. She is doing a lot of outreach to individuals who have children with complex medical issues. She met with a legislature, Kim Fosset who is going to help her put together a forum in a few months.

Laura – She has been working with Medical Home and is finding it challenging. They have held their forums and had good parent participation. She has been working with Alice & will be giving a presentation to DDS Sept 17th to try to get more support in the Litchfield /Torrington area. So she is doing a lot more presentations and a lot of PPT's. On the CCMC side her center is being aligned with primary care. They are meeting with Dr. Antonelli they will be having a more direct relationship with discharge planning and having a bigger role in the hospital.

Deborah – SICC – On the financial side the hot topics being presented are all related to Birth to 3. She can bring a report to the next meeting that outlines how they are responding to calls, etc. On the autism specific program, the big news is that there is coverage throughout the state. One of the biggest topics has been safety specifically for the counselors going into the home to help educate the agency as to what they can do to get information out to their employees on home safety & what to look for. Deb mentioned that the B-3 provider newsletter has a section on home safety. She offered to send it to Karen who will then distribute on the listserve. They are also doing their by-laws and reviewing the process for focus monitoring. Focus monitoring is focusing on what they do and reviewing the entire process to see if it is actually working or not. The national accountability conference is coming up in Baltimore Aug 25& 26th there have been no new complaints for mediation. She attended a presentation called the Early Intervention Family Alliance. It is similar to what we do except on a national level. As a support group for people who work with these types of organizations and want to get more out of them by helping the leaders to connect to get more out of their own meetings. They also share information on national news & laws. Deborah offered to post a link for us.

Next Meeting

There is no meeting on August 14th. The next meeting will be the annual retreat on a date and at a location to be announced.