

**FAMILY SUPPORT COUNCIL**  
**Monthly Meeting**  
**September 11, 2008**

Date: 9/11/2008

Place: CDHI

Time: 10:00am –12 Noon

**Attendees:** Chris Sloss, Jenn Carroll, Karen Hlavac, Mona Tremblay, Ann Tetreault, Colleen Hayles, Robyn Trowbridge, Joan Bachelder, Lisa Allyn, April Dipollina, Deborah Pagano, Tom Brooks, Eveleen McDonald, Lisa Sheppard (via conference call), Terry Cote, Laura Knapp, Karen Zrenda, Ann Gionet, Alice Buttwell (via conference call)

**Recap of Retreat Minutes:**

Terry gave a brief recap of the retreat.

2007 top three priorities were

1. Making sure that children and families have health insurance
2. That their system of care is coordinated & integrated
3. Quality Workforce - that the staff are available, trained and can provide good care.

We reviewed the past years accomplishments

We then had agency updates from DDS, SDE, COC, OCA, FSN, and the membership committee.

We identified the current needs and issues for families, and many of the same themes came up as in years past. Issues around workforce, healthcare, care coordination, health insurance, autism, transportation and accessibility.

We spent the last part of the meeting prioritizing action steps for the coming year and developed seven major categories. We then voted on the priority by each of us identifying the areas that we would be willing to work on. This helped us to establish our committees at the same time. The top three priorities identified for 2008 were:

1. Education (Co-Chairs will be Angela & Colleen)
2. Healthcare & Insurance (Co-Chairs will be Karen, Jen)
3. Family Support/Respite.(Co-Chairs will be April, Laura, Mona & Joy)

By-Laws/Statute CTFSC Legislation - the membership committee will continue to work on this as an ongoing council initiative

The next steps for each of the subcommittee's would be to meet and start developing some action plans.

- Determine what legwork needs to be done to gather information on these issues
- Research what work has already been done so we don't duplicate efforts We want to know what is out there so we know what to support and what our stance is.(ie catastrophic relief fund information is still the same we just need to identify a new possibility for a funding source-The healthcare financing committee is addressing this) Results may be to write a letter or testify to support this.
- Create a fact sheet that we can all speak from that is uniform
- Identify priorities
- Provide some suggested solutions and/or policy recommendations

### Please plan to report your progress at the next council meeting

Karen Z offered to work with Chris to simplify the retreat minutes & make it into a working document for us all by simplifying our priorities . **We want to have at least a comment or paragraph from each of the agencies (and/or parents) stating any issue they might identify as an area of importance to them. As our partners, if your group has not yet submitted a statement could you please bring something with you to the next council meeting?** We would appreciate your feedback. We will then include it in our document of our annual work.

Moira & Karen Z are going to meet to present a plan and make policy recommendations for those items identified at the retreat that did not fall into the top three category. Some of the categories can be addressed by writing a letter expressing our concerns to the agency that handles that program. **Karen & Moira will present their ideas at the next council meeting and we can discuss whether or not we want to endorse it as written or recommend an alternative.**

Questions:

We need to prioritize our issues this fall and talk about what our events will be & how all of the subcommittee plans fit into this strategy. **At the next council meeting we will need to determine whether or not we want to have a legislative breakfast and a forum or combine it to make it a larger legislative event.**

- Do we want to have a large forum (as in the case of family support) and if so, what outcome do we wish to achieve with this?
- Do we want to take a family scenario & demonstrate to the legislatures their experiences from birth-transition highlighting links to pieces of legislation we are trying to pass or at least bring an awareness to a need that we see and begin some dialogue

- Do we want to reshape the way we do the legislative breakfast and “create this blueprint for how we do our breakfast and use this as our agenda when we organize the legislative breakfast”

### **Together We Will conference RFP**

Jen mentioned that this conference is the annual B-3/B-5 conference. It will be April 2, 2009 at The Holiday Inn in Waterbury 9-3:30pm There is a RFP for presentations for the breakout sessions. These need to be submitted by October 9<sup>th</sup>. The subject matter of this conference is “Serve, Support and Include children with special health care needs.” The FSN is working on the DPH Medical Home grant that is around parent professional partnerships so they are going to submit along with CHDI a proposal to do a breakout session on parent professional partnerships and what family centered care is supposed to look like. It is there hope that the council also proposes to do a presentation as well.

Karen & Laura were thinking of submitting an RFP on behalf of the FSC to present also at the conference. They were thinking along the lines of “families as advisors” The do’s and don’ts and different roles that families can play in our society. Perhaps put together a panel. Terry suggested that perhaps the council could partner with the Commission on Children and their parent leadership training. The council agreed that this would be a good idea. **Karen offered to put together an abstract of what we want to submit.** Karen welcomes any suggestions or thoughts so please call or e-mail her with your feedback. If this becomes a presentation that we like Karen also suggested taking this on the road to try and help families get into more leadership roles.

### **Several Flyers were passed around**

- Colleen shared her document “Before during and after the PPT” with the group. This will soon be available on the SDE website as well as their Helpful Resource Brochure. (I have attached a copy of the PPT doc for those who missed the meeting)
- Open House sponsored by the Regional Planning & Advisory Council for 9/23 in Clinton. (They will be doing this in all regions). The topic is “Learn how you can make a difference in the DDS system through involvement and advocacy. This is about educating people about what is out there that they can get involved in that might help make legislative change. There will be many advocacy groups represented at this meeting
- Karen H distributed a flyer noting that the Legislative Program Review and Investigations Committee is conducting a study on *Planning for the Needs of Aging Individuals with Developmental Disabilities* and has scheduled a briefing meeting for the study on Sept 23<sup>rd</sup> at 11am. The Public hearing is scheduled for the same day at 1pm at the LOB. This will probably lead to some legislation and pressure on the executive branch in certain areas. (I have attached the Scope, briefing and Key points from this meeting)

- Jen shared a flyer on the 2008 Disability Convention and Expo on Sept 27 10-4pm at the CT Expo Center. They invited legislators to speak and offer tips about how to communicate effectively with your state officials on disability related issues, there will be many vendors for parents to speak to about the many services available for children and adults with disabilities, and many activities are planned for the children.
- Jen then shared some information about CT PIRC – CT PIRC stands for the CT Parent Information Resource Center it is housed at SERC(?) The services of PIRC include Family support, resource, training and outreach targeting families of culturally and linguistic diverse backgrounds. The primary work of PIRC focuses on No Child Left Behind. They provide toll free assistance related to No Child Left Behind, they do a lot of professional development around Title 1 to districts and staff around the state, there is a tool kit which Jen handed out about No Child Left behind. For more information about PIRC visit their website at [www.ctpirc.org](http://www.ctpirc.org)
- The Commission on Children is having an obesity forum at the legislative office building on Nov 7<sup>th</sup>. If you have idea's for ways this event can include a speaker topics, or materials on anything relevant to how obesity effects children with special health care needs please get those ideas to Tom soon as possible as they are finalizing their plans. (Jen offered to send Tom some idea's on how to promote getting special needs children outside and playing in their communities)

**Meeting Locations:**

We all agreed that we like to continue to have our meetings at CDHI since the location is good for many of the members and it's FREE. We would however, like to have at least one council meeting a year at the LOB particularly when they are in session.

**The next Family Support Council meeting will be held October 16<sup>th</sup> from 10-12 noon at The Office of the Child Advocate**

**Adjournment:**

There being no further business to come before us, Motion to adjourn: Robyn; Second April. Vote: Unanimous  
Meeting adjourned at 11:43pm.

Minutes respectfully submitted by,

Chris Sloss