

FAMILY SUPPORT COUNCIL MONTHLY MEETING MINUTES – OCTOBER 8, 2009

Meeting called to order at 10:15 by co-chairs, Karen Hlavac and Karen Zrenda

Welcome and Introductions

Voting Member Present: Kathy Bradley, Mary Beth Bruder, Alice Buttwell*, Sylvia Gafford-Alexander, Ann Gionet*, Colleen Hayles, Karen Hlavac (co-chair), Merva Jackson*, Moira O’Neill, Kathy Reddington, Lisa Sheppard*, Robyn Trowbridge (Secretary), Karen Zrenda (co-chair), Mona Tremblay*

Other: Thomas Brooks, April Dipollina*, Hal Giber, Tesha Imperati, Aileen McKenna, Maureen Smith, Virginia Pertillar (Citizens for Quality Sickle Cell Care, Inc.)

Public Comment

Virginia Pertillar gave a brief introduction as she is the new Executive Director for Citizens for Quality Sickle Cell Care, Inc. She has taken the place of Liza LeGrier, who has relocated. She would like to continue the partnership with the FSC.

MOTION

Approval of Minutes

July Minutes - Changes: Remove Maureen Smith (OHCA) as a voting member. Correct the spelling of Karen Hlavac’s name. Motion made to accept the July minutes with noted changes by Moira O’Neill (OCA). Seconded by Robyn Trowbridge. All were in favor. Motioned carried, July minutes accepted.

MOTION

September Minutes - motion made to accept the by Mona Tremblay. Kathy Bradley seconded (DCF). All were in favor. Motion carried, Sept minutes accepted.

Legislative Updates

Kathy Reddington (DDS) shared recent legislation that directly affects the Family Support Council. She will email copies out to the Council members. Tom Brooks (COC) had copies to share at the meeting. In summary, all appointed members will serve no more than eight consecutive years. If an appointing body (Governor and legislative leadership) leaves his or her position, the appointed individual can un-appoint the member appointed by a previous appointer, and re-appoint another person to the Council.

Some legislative updates were mailed out to the Council by Chris Sloss – which was a compilation done by Beth Leslie of the Office of Protection and Advocacy. One change was the Medically Necessary Definition that many of us were following and advocating against. The purpose of the bill was to amend the definition of medically necessary for the purposed of paying insurance claims and its goal is to reflect savings M. O’Neill noted that there is a Commission that oversees how DSS sees the definition of Medically Nessary. Sylvia Gafford-Alexander(DSS) will look into the mechanism for getting on the Council as this may be a good membership for a FSC member.

T. Brooks shared the comptroller has warned the state may be going into deficit again to the tune of \$500 Million. Suggested FSC members keep a line of communication going with legislators about what programs cannot be cut any further. The Governor may be addressing this soon.

Also, the Speaker of the House (Donovan) has put together a task force “Children of the Recession”, comprised of members of congress and parents. They will hold regional hearings in the districts this fall to identify legislation. Their agenda is to protect children and families during the recession. T. Brooks has a summary available from the Commission on Children’s presentation on the affects of poverty and the recession on children. Of note, the census bureau annual poverty statistics revealed that of the 50 states, CT had the largest one year increase in child poverty and family poverty as well. Council members and families should be encouraged to come out and testify as the Speaker of the

House has pledged there will be legislation around this issue. We need to be sure that CSHCN are at the forefront and not forgotten. S. Gafford-Alexander suggested that we go to the legislators, we need to have suggested solutions in our testimony. SNAP Training and work of DSS, COC working with communities, var. agencies have applied for reimbursement of 8.25 million \$\$ to come back to the state to address poverty reduction. NY State is already bringing in \$190 Million. Collaboratives have formed to address child poverty. Discussion ensued and it was suggested this topic be included on a future agenda. NY State is already bringing in 190 million \$\$

Maureen Smith (OHCA) shared that legislation creating task force to address "Sustinet" passed and was funded with 2 positions. Committees being created now – potentially could be model for country. The details of this program are to be worked out, but basically this is CT's attempt to look at universal health coverage – include folding in existing programs and expanding model of Medical Home. Autism Program expanded – now will cover ABA therapy up to \$50,000 / yr – coverage for under the age of 14 – will help a lot of kids. Concerns exist around how insurance companies/families would find licensed therapists. Colleen Hayles (SDE) noted that the State Dept of Education is working on regulations regarding this new law.

T. Brooks (COC) noted that COC is open for business despite a long and arduous year in which the new budget cut over ½ (53%) of their funding. COC has continued to keep their focus on mission. Thank you to those who spoke and testified on their behalf. However, it appears there is to be another significant cut imposed. It is being considered now.

K. Zrenda made a motion to support COC by writing a letter from the FSC. Motion seconded by R. Trowbridge, noting that what is most impressive regarding the COC is the revenue being brought to CT by them. The valuable information they bring to CT makes it a publically justifiable reason not to cut their funding. The motion was carried. Abstentions: K. Reddington (DDS), A. Gionet (DPH), C. Hayles (SDE), K. Bradley (DCF)

MOTION

Retreat Recap

K Zrenda gave brief update on retreat which was deemed a success and positive day. Chris has put together a compilation of the details of accomplishments for the past year as well as our strategy for the upcoming legislation, much of what will be determined by final outcome of the budget adjustments. While coming up with new programs and funding would be most challenging, it was decided that the FSC members need to be sure they are represented well on the various task force groups and commissions being created to explore funding options and legislation for children to ensure CSHCN are included in the discussions and plans.

Officer Election

Motion made to elect Robyn Trowbridge as co-chair of the FSC by M. O'Neill, seconded by K. Zrenda. All were in favor, motion carried. Abstentions: K. Bradley (SDE)

MOTION

Listserve

The group would like be able to use a listserve that is used by network members and coordinators, state agency staff, families and members of the community. It was so helpful in the past to have input from various sources when working with families and resolving issues and questions. K. Zrenda offered to get a listserve in place and will work with a few other members to get this going again.

Agency Designee – Voting Rights

OCA can appoint a designee to vote, per letter from Atty General Blumenthal. Group would like to explore having this determination for other agencies such as Office of Protection and Advocacy (OPA), Commission on Children, State Interagency Coordination Council (B-3). Suggestion made to get written opinion. K Zrenda will contact Jim McGaughey at OPA.

Funding for Administrative Support for FSC

K Zrenda reported that there are a couple ideas being explored. We are still open to suggestions.

Annual Recognition Award

R. Trowbridge made a motion to table this agenda item to next month. K. Reddington seconded the motion. All voted in favor, motion carried.

Family Support Network Updates

Lisa Sheppard – SW – shared a proposal from a group of families that have children who are aging out of the system and programming/service options. They would like to form a non-profit organization.

Tesha Imperati – SC – shared her associations with an Employment Group committee, Pediatric Family Advisory Council at Yale-New Haven Children's Hospital (YNHCH), Sibshop at YNHCH. Much of her time is spent going to PPT's with families as schools are cutting back on services.

April Dipollina – SE – involved with planning of three forums for families in Middletown, East Lyme and New Haven to address what families can do if they do not have a case manager (due to budget cutbacks). Flyer will be forthcoming.

Mona Tremblay – NE - support groups are up and running; collaboration with medial home partnership is getting better and she has been involved in social skills group and other presentations

Alice Buttwell – NW – continues the Milford Support Group; ongoing outreach efforts and involvement with the New Milford Sibshop

Agency Updates

Sickle Cell Conference: New Research, www.accesstv.org – channel 13 – Sickle Cell

K Bradley (SDE) – Vol Svcs – are accepting referrals. Passed out description of program. Also shared new organizational chart. She will email out to members.

Aileen McKenna (DDS-B-3) – Birth to Three fees are increasing by 60% . Obviously, B23 did not want this to happen, but it was in the Gov's plan – initially was going to be doubled. Also, it used to be that families had 2 months reprieve for fees – this is no longer the case, so fees go in to affect first month. This will be effective Jan 2010. If you lose your job, B to 3 services are free.

A. Gionet (DPH) - Sent Chris Sloss info on the toolkit training Fri Oct 26th at Hospital for Special Care; the H1N1 Flu Hotline is 800-830-9426 (seasonal flu also)

S. Gafford-Alexander (DSS) Brain Injury Conference - Oct 16th Tunxis Comm Coll \$25 fee; Grant App for TBI – looking for partners – would consider inviting FSC as partner in the competitive grand. FSC would need to agree to provide training outreach Will discuss again.

C. Hayles (SDE) - PPTs plain language translation of requirements and regulations need to be available to families effective Oct 1st – were disseminated to all Special Education Directors a week ago & will be in the Bureau Bulletin on the website. Also, there was an identified need for training for people chairing PPTs – going to be available through the RESCs (Regional Education Service Centers i.e. LEARN, ACES, RESCUE, etc)

K. Reddington (DDS) - \$500,000 (new \$\$) is still in budget to continue Home Care Pilot for families with needs of over 20 hrs home health aide. Families were having a problem getting this coverage. DDS would allow families to direct and hire own people. This is good for families – when over 20 hours, difficult to keep staff and have continuity. Person would have to go through DDS.

MOTION

Motion to adjourn by S. Gafford-Alexander; C. Hayles seconded the motion. All in favor. Meeting adjourned at 12:23 p.m.

Karen Zrenda