

Connecticut Family Support Council
Monthly Meeting
January 14, 2010

Place: DDS Wallingford with call-in option

Time: 10:20 a. to 12:30 p, (starting time was delayed due to late arrival of members)

Facilitator: Co-chair Robyn Trowbridge

Recorder: Robyn Trowbridge and Moira O'Neill

Participants:

Voting Members: Bruder, M (on phone), Butwell, A. (on phone), Carroll, J., Dipollina, A, Gafford-Alexander, S., Gionet, A., Harris, S. (on phone), Law, J., O'Neill, M., Reddington, K., Sheppard, L., Trowbridge, R., Zrenda, K.

Guests: Imperati, T., Pagano, D., Pertillar, V. (on phone)

Call to Order 10:20 am

Public Comment

Jen Carroll has been selected to participate in a training program for rising leaders in nonprofit industries. Congratulations Jen.

Approval of December Minutes: Alice Butwell noted some corrections to statements she had made. Delete "who are losing access to utilities due to decreased income" and "and Early Childhood Alliance"

A motion to accept the minutes as corrected was made by April Dipollina, seconded by Jen Carroll. All approved. Joan Law abstained.

Elections

Lisa Sheppard suggested an agency member in the role of secretary would balance participation with the parent co-chairs. Jen Carroll agreed and felt there could be opportunities for agency in-kind resources. Jen nominated Moira O'Neill. Karen Zrenda seconded the nomination.

A vote was taken and all approved.

General Business

The grant from the DD Council paying for staff support has been audited and \$2500 is still left. Robyn Trowbridge will contact the fiduciary to determine whether that is a lapsed billing or the funds are available for continued staff support. The funds must be spent by June 2010.

New Business

Sylvia Gafford-Alexander of DSS described a \$10,000 grant available to the FSC through the TBI Initiative. The expectation would be that the FSC would sponsor outreach and education among parents of children with chronic conditions or disabilities who may have co-occurring TBI. Some of the funds may be used for staff support and supplies.

Discussion ensued regarding incidence of TBI among children and problems encountered with medical diagnosing. Significant knowledge deficits were described among providers and parents.

There will be training for TBI educators on January 29, 2010 at the LOB. Chris Sloss, Karen Z., Robyn T, April D, Lisa S, Sheila H, will all attend the training. After the training there will be a planning meeting with other partners in the TBI Initiative (Commission on Children and Fatherhood Initiative). The initiative should culminate in a forum.

Ann Gionet will post a resource about injuries to children on the list serve

Discussion followed about current initiatives in TBI concerns. The Children's Trust Fund has a campaign and there is a multi-agency injury prevention group that promotes prevention of shaken baby injuries.

Moira suggested that the FSC invite people currently involved in such efforts to speak to the FSC in order not to replicate and perhaps to enhance/build partnerships.

Motion – Karen Z. motioned that the FSC accept a proposal from DSS to partner in the TBI initiative grant; Joan L seconded. All approved. Sylvia G.A> abstained.

Sheila Harris said that AFCAMP is doing a TBI parent training with P&A.

Legislative Breakfast:

March 3rd

Moira explained that the family survey about budget impacts on services has to be approved by DDS IRB. Application will go in 1/15/10 and is expected to be expedited. A link to the survey will be posted to the list serve and FSC websites. Agencies able to post the Link are also asked to do so. The survey is accessible on line through Survey Monkey. It can also be printed if participants request such assistance.

Families willing to give testimonies about their current experiences and concerns at the Legislative breakfast can be recruited prior to the survey and annual report. The theme will be about the economic impacts on families and state services. Chris Sloss will be asked to keep a central list of family speakers and their topics so they can be organized at the breakfast.

Save the date notices can go out now. April and Jen said they will work with Chris in planning.

FSC Provider Award:

Robyn T. reported that Alice made an exceptional and appreciated effort to identify nominees in the community. There were a total of 5 nominees statewide. ARC of New London County will receive this year's award for their establishment and support of a summer camp that was operated at Camp Harkness in the summer of 2009.

Agency Updates:

FSN Updates:

Jen C - Community Renewal Team of Hartford asked for assistance to do parent advocacy training. There will be a FSN meeting 1/22 with guest pediatrician from CCMC. Also, 211 Info line will be represented at next meeting.

Tesha I. – Busy with PPT meetings, Next Medical Home Forum topic will be dental care

April D. – 2/2/10 presentation on Social Security Benefits and Guardianship – watch for list serve posting.

Lisa S. Families still confused about whether they have case management; assisting parents with their own disabilities, so helping entire family

Alice B. – Will be starting a new support group. She is planning to join the parent work group with SDE Special Ed. And may be on a task force for people with developmental disabilities in hospitals

Sheila H. – They have a lot of new parent leaders/advocates. A newly started training had 15 parents participating and 15 more expected to participate. On 2/22 there will be a program on Strategies for Children in Schools with ADHD and Autism. Also there is a new IEP form being used in Hartford schools and they will be doing a training to use that.

DPH Ann G., Survived budget anticipated budget cuts, still unsure about deficit mitigation.

B-3 Deb P., 1/25 meeting at 9:00 to discuss different ways to document impact on increase in fees. They are planning a retreat and would like FSC retreat outcomes to discuss/integrate. Karen Z said she will send report from retreat.

DDS Kathy R. – Employment First Initiative with Bureau of Rehab Services received federal dollars to pass on. The program is designed to ensure folks with developmental disabilities are in competitive employment instead of day programs.

OCA Moira O. – Current projects on transition planning from institution to institution; as well as a project on mental health care and treatment in corrections. Families with concerns about children's care in corrections should contact OCA.

Parent and Guest updates:

Bruder, MB – Pappanikou Center is: starting 3 “train the trainer” workshops on parent leadership; doing community outreach program on 2/5 with 300 people participating about evidence based practice; and on 3/29 a program on assistive technologies for children with disabilities in homes and schools. She will forward notices about these events.

Virginia P (Citizens for Quality Sickle Cell Care) – Adults with sickle cell clinic at UCONN on Tuesdays and one at Yale also. An online TV program about newborn screening can be found on www.accesstv.org.

Joan L – noted that Children’s Rights from NY, the organization that threatened a law suit if voluntary services were to close is looking at the question of whether children with mental retardation are included in the discussion. She encouraged parents with concerns to call the organization; the number is on line at childrensrights.org

Wrap Up

Robyn T asked that all agencies, network coordinators, parent members and guests submit updates in advance of meetings as a time-saving measure. Moira said that she would accept and consolidate updates. Please send your monthly updates and notices to moira.oneill@ct.gov at least 2 days prior to an FSC meeting.

Karen Z. motioned to adjourn the meeting. Alice B. seconded. All approved.

Adjourned at 12:30