FAMILY SUPPORT COUNCIL
Annual Retreat

August 22, 2008

Attendees: Terry Cote, Karen Zrenda, Jennifer Carroll, Joan Law, Angela Spino, Sylvia Gafford-Alexander, Tom Brooks, Laura Knapp, Mona Tremblay, Chris Sloss, Lisa Sheppard, Molly Cole, April Dipollina, Terry Walsh, Ann Tetreault, Robyn Trowbridge, Colleen Hayles, Mary Jean Schierberl, Sarah Liebeskind, Joy Liebeskind, Tesha Imperati, Moira O'Neill, Mike Selvaggi

Introductions & Ice Breaker: We had a good representation of the group present and had fun sharing our favorite food "or beverage" to get the morning started.

Last year we had 3 basic priorities for the year:

Health Insurance
    Family Opportunity Act
    Children's Waiver
    Insurance for adult caregivers

Ensure the availability of a coordinated and integrated system of care for children
    The way that we saw that we could get that was through Council Legislation
    Membership coordination and integration
    Funding for the council
    Ensuring data is available
    Ensure funding for the network

Quality Workforce
    Training for staff
    More options
    Standards for staff
    Non medical as well as medical staff
    Promoting the Family lives model in CT

Past Years accomplishments: The team has a lot to be proud of particularly our network people whom as you can see many of our accomplishments reflect their hard work this past year (** codes represent © for council, N for network, NC for both)

Charter Oak for Adults - an accomplishment for the state as opposed to this group but worthy of noting as this was a big issue last year for a lot of parents. This is still very new – website so new no way of knowing if doctors in your area are buying into it. Provider capacity is not there yet.

Funded the position for the council _©

Visibility of the council (i.e. legislative breakfast & involvement in the legislative process) Developed good relationships ©

Work on Catastrophic relief fund - Tom mentioned we are still hearing from legislatures now who are still interested in that piece of legislation even though it did not succeed this year "so try, try again" ©

Katie Beckett – in 2007 we got 20 more slots for this waiver – implementation to fill those slots are in process ©

Participated in the bullying forum © - was a success because we passed a substantial bullying legislation in years placing new requirements on schools

Family to Family Grant – Health information network participation – 3 yr grant beginning in June (an expansion of the old grant) (N)

DPH Medical Home initiative grant partnering with CDHI to provide training to parents and pediatricians around what is a medical home has been going very well. Their role alongside CDHI is to provide education and training to families and pediatricians across CT as to what a true Medical Home model should look like and how to build strong and effective parent/professional partnerships. The FSN has completed parent forums in all (6) regions, and is in the process of planning a statewide forum directed toward a wide audience of parents and family support professionals. (N)

In 2008 within the B-3 system the FSN is participating 100% to provide service coordination training and has been working with B-3 management to plan training which will take place later this fall. The parent faculty continues to bring unique ideas to the table that will enhance the learning process for trainees while also providing a parent perspective to the early intervention process. This strengthens their parent collaboration so it increases their visibility, credibility & people are now starting to see the FSN as a real resource. (N)

The FSN now has a working toll free number 1-877-FSN-2day (877-376-2329). New brochures have also been printed this summer with all new contact information and are available through the FSN staff members. (N)

Website updated –The FSN continues to use the website as a source of outreach to families and providers. The calendar has a listing of regional events and they are working toward having an extensive linkage to regional and statewide supports posted as well. (NC)

Family Lives – plan to replicate in CT, SE network co-sponsored a conference on autism parent & provider education, (N)

The council & the network were represented on the Camp Harkness Advisory Council & through this council there have been a lot of improvements to the camp. There is also an initiative (which almost happened this camping season) to start an autism specific camp. Due to time constraints & to ensure quality of the program they decided to postpone until next year. Another initiative they are working on is bringing back the "day camp" they had in the past as an after school program (NC)

Printing of "Special Ed Made Easy Guide" and "IEP Guide" (Collaboration of N, DDS & PNA, DD Council) The DD Council was responsible for covering the cost of the printing of these materials

Regionally and statewide, the FSN provides opportunities for families to receive training and access to workshops and resource events. The FSN staff work with various organizations in planning & preparation of family support events, host resource tables, speakers and share information broadly that impacts families as well as providers and state agencies. (N)

FSC was represented on the DPH Medical Home Advisory committee – ©

The listserve has grown – should we have 2 listserves – one for appointed members & one for others? ©

The legislative breakfast was a great success ©

Identify Current Needs & Issues for children & families

Waiver for children - (why) we want a children's waiver to get (a) access to a broad range services beyond what you get with a Medicaid card (Medicaid waiver services) (b) looking for access to Medicaid insurance

Care coordination to look at each families needs and the services needed to meet those needs

Accessibility – Home modifications, ramps, etc.

Workforce – inadequate workforce for in home supports, need workforce for children with autism, , need training (Even families with waivers are struggling to keep trained staff in the home)

Benefit package for home health aides and nurses & funding for that –(no benefits contributes to the limited workforce for in home supports)

Before and after school care (numbers increasing, need for the very young-adults)

Respite (waiting lists, not enough - rarely a provision for an emergency need)

Families would like to have separate DDS phone # for DDS Voluntary Services

Supports for families of children with autism/aspergers (large number of calls coming in & the system doesn't have much to offer)

Extended school year for families that need it – Systematic educational (PPT) advocacy support, Behavioral support needs in school, community & at home, they need a behavioral assessment, treatment, positive behavioral support staff, help with inclusion

Expand autism pilot across the state

Expand Medical Home practices

Charter Oak Health Plan– Hospitals and providers needed

Support services (lack of providers) are absent in rural areas of the state whether direct hire or agency

Transportation (by bus primarily in day)-many parents would like to attend evening meetings, PPT meetings or all day seminars but do not have any means to do it

Families/children can't get to the "joy" in life because there are so many roadblocks for them. Need mentorship perhaps to help support and bridge the gap.

Medicaid for children going back to managed care – appeals for denials, etc are going to the managed care organizations, not DSS, so your sole source of appeal is to the company that already told you NO. (DDS – check if children required to go to managed care or fee for service? Children who were switched to fee for service Medicaid through requests from DDS case managers may be inadvertently switched back to Medicaid managed care when their families are converted back. DDS will follow up with DSS and Terry will report back.

Smaller DDS case manager caseloads – especially those who have voluntary services

KASA – needs around transition & access to job opportunities, the military or college

DCF voluntary services – not enough hours in home support – staff not trained in specialized areas to help families to support child in family ("all part of the workforce issue--- so a workforce we perceive that we have available to us is completely inadequate")

Children's involvement with legal services – family has no resources

Restraints and seclusions in schools – the numbers are increasing. Families need advocacy at PPT – families have nowhere to turn

BRS supports inadequate – don't often support college. Their role in the school system & transition is limited to supports for employment.

Connect-ability resources could be an option to develop volunteer opportunities? (Sylvia offered to ask BRS how they are assisting with transitions & if they are focused on career/college if a student wants to do that & report back to the council)

Tunxis offers a Traumatic Brain Injury program that offers a series of courses & training so that we have a better prepared group of service providers & caregivers to assist with cognitive and behavioral issues

Explore the idea of having a diaper bank in the eastern part of CT

State Dept. of Ed – no data taken on restraints & seclusions (we should try to identify top 3 systemic issues (specific areas) districts/families are having consistent problems with so we can create some dialog between SDE & Council & perhaps have a focus monitoring session) (We should partner with CPAC on this) **Molly indicted that it would be very easy for her group to capture the "hard data" that we need to push things to the next level- they already have a system in place so between her group & CPAC's data we should be able to come up with some "real data"

Spanish speaking families – making sure we always have training & support for them

Agency Updates

DDS:

DDS Voluntary Services Program for children eligible for DDS services who have behavioral health needs has partial year funding that will allow them to expand by 90 children this year. DDS VSP will institute some new things this year with families (i.e. an agreement with families that they understand that there are certain conditions for participation –for example: families should be present 50% of the time when in home support services are taking place and include behavioral supports as part of the plan.)

DDS is participating in "the money follows the person program" (MFP) – where the goal is to support folks to leave institutions (they are helping 70 people served by DDS to transition out of institutions over 4 years & they are working closely with DSS on that - While most will be adults in long term care, children in institutions will also be considered.

DDS is hoping to get approval from OPM to put in a budget request to transition additional DSS Medicaid funds to DDS for home health services. If additional funds are transferred, they can hopefully cover at least the home health aide supports for some additional individuals.

DDS has expanded their autism pilot program.

DDS has some legislation in again this year requesting to be able to have information about DCF's registry to be aware in hiring practices when folks have a substantiated history of abuse.

SDE:

They indicated that Focus Monitoring of Districts by the SDE was generated by Suspension and Expulsion data last year and that support in that area continues to be provided to districts who continue to require assistance in reducing the suspension/expulsion of special education students. The issue for focus monitoring next year will be Academic Achievement of students and data regarding special education student achievement will drive site visits to districts in the Spring.

The SDE's priority is about closing the achievement gap through early intervention, literacy – the No child left behind – and they will do this through school wide literacy focus on reading, curriculums etc.

Commission on Children:

" In general, the Commission's work will cover its usual categories of healthy, safety, learning & economic security. They will continue their work on bullying, childhood obesity, child poverty reduction, early childhood education, parent leadership and other related children's issues.

In terms of issues related to children with special health care needs, the Commission staff is interested in the direction that the FSC takes on its priorities, and they look forward to partnering wherever possible. They hope the council will consider the following priorities:

Catastrophic Illness in Children Relief Fund---legislation to establish a fund

Katie Beckett Waiver – authorization of an additional state waiver

Family Opportunity Act – advocacy & research work to move toward legislative action

An expanded Family Support Network, with the involvement & support of more executive branch agencies (in $$ rather than seeing one state agency doing it)

A state forum that advances the councils legislative goals and expands public awareness (ie education forum something like the institute with more visibility using technology- we would use real life stories and involve folks from different agencies, advocacy groups & communities& bring them together to work through these problems identifying specific problem areas in the systems & specific solutions)

An improved website and communication network for family support (UConn has a research team that offers their services—can we link to them as a resource?)

Office of the Child Advocate:

1. The OCA has several legislative priorities this year but where children with special health care needs are concerned, they will focus on a children's catastrophic illness relief fund. This would be a fund available to reimburse parents for catastrophic costs related to a child's illness or injury that is not covered by any other means. Similar funds in New Jersey and Massachusetts have been useful for covering extreme medical costs related to uncovered surgical costs, medical equipment, home alterations, and other costs associated with a child's medical needs but not typically covered by medical insurance, such as electrical bills for running medical equipment, ramps and gas for transportation to medical appointments. The issue will be where the funding source will come from – as it does not appear it will be successful coming from business' even though that has been successful elsewhere

2. As a long term goal of establishing additional Medicaid waivers and/or the Family Opportunity Act, the OCA is continuing to work with the Catalyst Center analyzing Katie Becket Waiver expenditure data to get a better idea of the cost of implementing more means of access to Medicaid for children with special health care needs. They expect that will be ongoing through the Fall with development of recommendations and an informational packet through the year.

FSN – The FSN has been working hard in all (6) regions to offer and participate in family support activities. This includes running multiple parents support groups (a new group was started in every region), providing 1:1 parent support on the phone and in person, collaborating with state agency representatives and advocacy organizations and serving on their boards, advisory committees and in other capacities, outreach to communities, school districts, faith based organizations, recreation departments and volunteer organizations-all in an effort to improve family support in CT and ensure that families are linked to all possible services and supports available. This time of year keeps the FSN staff very busy with education advocacy and PPT meetings. The impact they are seeing on parents is the pressure of a reality that systems are often not available to meet the needs of the child, and solutions are difficult to find and often take a long time to see through. Additionally, healthcare access is a huge issue for families-all aspects impact families raising children with special needs and disabilities. Healthcare costs, financing, access and quality are issues the FSN hears about regularly. (N)

<u>Membership committee update:</u>
Initially started with a recap of the meetings surrounding the Bi-law revisions by Joan Law. We have more work to do on the bi-laws to get them more inline with legislation. In regards to the bi-laws there will need to be some changes to the statute that will need to be addressed to bring everything into alignment. Tom Brooks was going to look into what would be involved to do that. Membership committee will be again meeting soon & will hopefully have everything together to be voted on at an upcoming council meeting (Tom mentioned the statutory changes would be a technical bill that would not be controversial the question is would the council consider advocating for a name change-does the Family Support Council (which is what we are in statute adequately describe the scope of the councils work under this statute? So we need to look at the duties under statute & think that through. Joan mentioned that this group was established to look at membership, bi-laws & gaps in membership, recruitment of new members etc with particular focus on whether or not network members can be voting members but you can see much more needed to be addressed before we could move forward.

We had an initial unofficial response from DDS that there may be a conflict of interest-the DDS attorney who questioned "would the networks exist without the council? Essentially the council created the networks. The group brought up that the grant went to the family support council so that the network benefited financially from that but it may be different now because the network is almost becoming a separate entity so it may actually not be a conflict as originally thought. The council can certainly ask for an official ruling from the ethics group. So we need to give some serious thought as to how we want our relationship to look like. Concerns noted that the network people have with not being able to vote is that they are "the voice" for families & are supposed to be voting for the families they are supporting so if this is taken away then they feel we will lose a valuable voice. The membership committee is trying to stay inline with the bi-laws and the statute.

The discussion then moved to appointments & Joan mentioned that Vicki drafted a letter that can be shared with key legislative people to hopefully move the process along for these appointments. They will share Vicki's letter at a full council meeting in the future. The membership group wants to expand the diversity of the group however we also recognize the need to get the spots filled as soon as possible by people who will attend and participate with us. They briefly talked about the forum & again trying to educate people as to what the FSC is, what we do so they are hoping that with help from the COC (Commission on Children) could we bring the whole concept of family support to a bigger venue so we have everyone on the same page. Lastly they discussed how they can bring new people “up to speed” who are new to us, visitors etc. as these are public meetings.

Priorities and Action Steps for the upcoming year: Establish sub committees by voting on what you would be willing to work on (i.e. flush out the issue & come up with some recommendations around it – also mention who is doing what around the state as many groups are already working on some of these issues already) In order of votes:

(1) Education: (Angela, Lisa N., Ann T, Jen, Laura K, April, Terry W, Molly, Colleen, Joy, Robin, Karen H, Deborah, Lisa S.) Co-Chairs will be Angela & Colleen

Identify systemic educational issues and bring to the SDE

Develop 1 page for families (a) meet with bureau chief (b) encourage sde to do focused monitoring on these issues (c) partner with CPAC & include data (d) establish educational subcommittee suggest Colleen chair include DDS & ED liaisons

(2) Healthcare and Insurance: (Tom, Karen Z, Laura K, (OCA) April, Molly, Mona, Brit, Joy, Jen, Eveleen, Maureen Smith, Ann G) Co-Chairs will be Karen, & Jen

- (a) Catastrophic Relief Fund
- (b) Charter Oak
- **(c)** Katie Beckett Waiver Status, additional slots/new waiver (can we create a less comprehensive waiver?)
- **(d)** Family Opportunity Act catalyst center – data, costs, fact finding

(3) Family Support: (Ann T, Tesha, Karen Z, Moira, Chris S, Joan, April, Laura, Mona) Co-Chairs will be April, Laura, Mona

Interagency Efforts:

- (a) Cooperative interagency coordination and collaboration - Clearly define what the council is so we can better partner
- (b) Identify agencies roles in supporting families – so DDS is not the only participating agency-get other agencies involved – present things their agency can do to be more involved-be more accountable to family problems

Family Support Forum:

- (a) Families, state agencies, providers, family stories show what it takes to get services, and hard data
- (b) consider survey, look at medical home survey data from Molly.

(4) Respite: (Joy, Lisa N, Mona, Terry W, Chris S, Robyn, Laura K, Molly) Joy to Chair

   (a) Before and after school childcare
   (b) Children with Autism/Aspergers – support the work of other autism groups
   (c) Transition BRS – support KASA, Connect-ability
   (d) Medical Home

(5) Improve Workforce: (April, Laura K, Robyn, Sylvia, Mona)
   (a) Quality staff
   (b) Training

(6) By-laws / Statute CTFSC Legislation: (Karen Z, Tom, Joan, Chris S) Joan to chair
 (a) Technical changes –consider name change
 (b) Continued funding for the CTFSC
 (c) Children's waiver – what would it take to get one started
 (d) FSN staff need a raise

(7) Accessibility / Medical Home modifications (Joan)

Adjournment:

There being no further business to come before us, the meeting was adjourned at 12 noon.

Minutes respectfully submitted by,

Chris Sloss