Child and Family Advisory Committee

Meeting Summary
May 16, 2006
Henrico CSB – Conference Room C
Glen Allen

I. Welcome and Introductions – Advisory Committee introduced themselves.

II. Approval of minutes – Motion to approve Dana with amendments, Katherine seconded the motion,

III. Celebrations – Pam is attending SOC conference in Harrisonburg, wondered if committee wants her to promote the conference at the SOC conference. VA INFO wants to identify 100 families across the Commonwealth to attend the annual statewide VA INFO conference. Professionals are responsible for hotel accommodations and registration fees. Hotel and registration fee will be paid for one family member to attend. Additional information and registration forms available at the Medical Home Plus web site. Maureen asked committee to identify families to attend the conference. The overall theme of the conference is how to facilitate family participation of boards, councils, and committees.

Monica Schlessinger-Smyth – Virginia Access is sponsoring a conference, funded by a grant from the Virginia Board for People with Disabilities. July 11-12. Call to Action conference will be held on May 20th. A summer camp for children in the Tidewater area for children with disabilities will be held this summer, for children age 8 and younger. For additional information about the summer camp, the web address is **www.pedlifeskills.org.**

IV. Parent Network Group – Monica Schlessinger-Smyth

- Certificates of recognition
- MAD will disseminate write-up to CSBs – final version end of May or June 1st.
- Meeting July 10 @ Medical Home Plus.
- Parents will like to present a gift certificate for winner.
- Winner announced at the VA INFO conference.
- Are there guidelines for logos – if one available, send to the committee.
- The family network will look at the Resource Directory (what's already out there for families to be aware of) and offer suggestions of what to add to the web page. Discussion about the resource directory related to collecting information about local communities' information, how would it be updated, should the directory only apply to information about state agencies, some local communities have already initiated pulling together resource directories for their local communities. 211 may be a resource for the parents to consider as they work on developing the resource directory, 211 was not geared specifically for families who have children

with disabilities and to provide information about disabilities. 211 staff will train Medical Home about accessing the database, etc. One idea, to do the state offerings or develop a template for dissemination across communities, this is what families need to facilitate development of community specific resource guides. Template could go to each FAPT teams, school districts, in each community the agency most knowledgeable about services, whoever took it on would be responsible for compiling the information. If the parents developed the template, CSA would ensure dissemination to the FAPT coordinators. Is there something already in existence, T-TAC on line, focuses on particular areas of a child's life, resource information has not been posted yet but will provide information about resources statewide. Each agency could be responsible for disseminating the directory to families.

- Report back to committee at the August meeting about policies. Network will discuss recommendations about them during e-mail.
- Jean will present a family story at the August.

V. Updates - OCFS

- SOC and DJJ/MH Transformation Initiatives – impact at the Commonwealth
- Early intervention transformation initiative
- 300-F update

VI. State Agency Reports

- DMAS – Deficit Reduction Act of 2006, looking at federal changes that may effect state regulations.
- DOE – looking at family life curriculum issues
- State Facilities Bed use - as a result of an OIG report, the Department is looking at facility bed utilization issues. There is one more meeting planned and the committee will publish a report.
- CSA – attending a national conference with training institutes with broad family participation, how to engage families more, to help professionals learn how to engage families. CSA is looking at outcomes, workshop recently with a national expert, agreement to work on one outcome, out-of-home placements for the agencies in the Health and Human Services secretariat. CSA is focusing on how to serve children in their own communities.

VII. Committee Priorities

A. Review of Policies
B. Resource Directory

VIII. Presentations

A. VA INFO – Dana Yarborough and Maureen Mitchell

Parent-to-Parent Program – there are 4 or 5 active programs statewide. The programs provide parent support. Since 2000 Dana is sole proprietor of Parent-to-Parent Program. Parent-to-Parent does IEP advocacy as well as working with families about other advocacy issues, developing information and materials for families, and connecting families with resources.

Family Voices – it has grown to at least 4 representatives in each state, heavy focus on health care and advocacy for health care and a heavy emphasis on policy. The work and philosophy varies nationally, carried out in each differently. In Virginia, no funding from national office in New Mexico, family to family health education grants were available nationally, some attempts at grant writing to secure funding, recognized the need for a coalition for an exchange of information for families. Priority for a coalition for Virginia, group came together and formed a coalition. Wrote a grant to CMS, received funding last October (2005). This is the key avenue for family voices to carry out their mission. Philosophy and mission; to provide information to families and collect stories to share with policy makers, reaching out to underserved populations, family-professional partnerships. Grant facilitated the VA INFO. The Maternal and Child Health Bureau (MCHB) was committed to parent-to-parent model, using efficacy study, health care frequently left off the table, funded by MCH Bureau and CMS. 31 states are funding by either one of the funding streams. VA INFO Center is located at Medical Home Plus; Care Connection for Children is a potential option for "housing" VA INFO. The Center was created to help answer the questions facing many Virginia families. Partnership for People with Disabilities is conducting an evaluation of the calls received by the Center. Formed a family support coalition, 96 members, local and state agency representatives, educators, family members, other organizations represented, focused on birth to 21, seamless system, protocol for triaging the calls to handle the volume of calls. National organizations want Virginia family network to focus on self-advocacy, self-determination, parents being very involved in their child's health care and family involvement in system transformation initiatives. There is planning for a shared point portal. The intent of VA INFO is to collectively connect the dots to assist families in a variety of ways. (**See handouts for additional information).** Family support groups are evident throughout the state with the exception of the Tidewater area and the Northern Virginia region. Coalition has 4 dream teams, to identify boards and councils with initial emphasis on state agencies, how to get appointment, funding, seek additional funding to help family participate, mentoring and training for families, know the policies, rules, regulations, and law, and the "politics" of various boards, and to bring family stories to state agencies to inform about impact of policy or law on families, testimony to legislators. One dream team focusing on

person-centered planning and is looking at best practices for person-centered planning, looking at all supports families need and who fills in the pieces, informal supports are integral to person-centered planning. Another dream team is looking at access to services, specifically in the area of family support. Linking funding and family support to community based services. What do families need to prevent out-of-home placement. Goal: training families to know their rights and how to empower them, to know what their options are and how to access those options. July 10th is the next meeting of the VA INFO Coalition from 10-2 at St. Joseph's Villa, looking for a permanent home; River Road United Methodist has offered the Coalition a "permanent" home.

B. Family Story – Randy

- Randy's daughter is 19, at the Florida Institute for Neurological Research
- Adopted Amanda through Henrico County, has another daughter, living in Hanover, Randy has 3 grandchildren
- First met and fell in love with Amanda while she was in foster care.
- Discovered a year after adoption that Amanda's biological mother abused alcohol.
- Did well through grade school. Mental health issues emerged while Amanda was in middle school. The remainder of her education occurred in the residential placements.
- Financial issues for the family around co-payments and deductibles for medication. Henrico DSS provided adoption subsidy for Amanda.
- Family did not have to relinquish custody for residential placement initially.
- Placed at the Pines in Norfolk in 2001.
- In Virginia don't have to take medications unless the individual is placed in an acute care facility. Pines would not keep her because of the disruptions due to her refusal to take medications; she was concerned about weight gain.
- Admitted to Commonwealth Center. Commonwealth Center introduced the family to the Florida Institute. The facility has provided good care for Amanda and has helped stabilize her. Amanda has been there a year and a half, taking her medication regularly.
- Adoption subsidy terminates when Amanda turns 21. Family wants to bring Amanda home, perhaps to group living for a period of transition, how to transition Amanda back to the community and to provide the necessary supports she requires.
- Hanover is working with the family on DD waiver. Hanover has offered to explore assisted living with supportive services.
- Randy is exploring applying for guardianship for Amanda.
- Randy's dream for Amanda, independent living.

Meeting adjourned.