

Family watch

Responding to Families and Friends of Children with Mental, Emotional and Behavioral Disorders

Virginia Federation of Families (VAFOF) Leadership Update

After many years and contributions as director of PACCT followed by VAFOF, Joyce Kube has decided to move on to a well-earned semi-retirement. We are delighted that Joyce will continue working with VAFOF in the role of Family Support Coordinator. In this new role, Joyce will nurture, support and expand VAFOF statewide support groups, provide resource coordination for families and providers, and participate in VAFOF Resource Team meetings and on committees that support these priorities. All of us at VAFOF and Medical Home Plus want to thank Joyce for her hard work and dedication as director of PACCT and VAFOF, and to wish her every success in her new role.

We are delighted to announce that Vicki Hardy-Murrell has accepted the VAFOF Director's role. As a registered pediatric nurse, the parent of a child with special needs, and a very senior Medical Home



Vicki Hardy-Murrell

Plus family support coordinator, Vicki brings a wealth of experience and energy to the VAFOF team. Her new focus will be on overseeing all VAFOF program activities, building a strong resource coordination team, and expanding the VAFOF statewide program. In addition, Vicki participates in a number of statewide leadership forums in the role of Family Representative / VAFOF. A few include the Virginia Mental Health Planning Council, Virginia State and Local Advisory Team, and the Child and Family Behavioral Health Policy and Planning Committee. Vicki welcomes your insights and input as she begins her new role, and can be reached at vhardy-murrell@medhomeplus.org.

Announcing the Virginia Integrated Network of Family Organizations (VA INFO) Annual Conference

Big news for parents and all who are dedicated to improving outcomes for children with special healthcare needs is the upcoming Virginia Integrated Network of Family Organizations (VA INFO) Annual Conference. This information-packed conference will provide an excellent opportunity for families, governmental agencies, healthcare and service providers, educators, and others to share information and insights that can make a real difference for Virginia's children and youth. This conference will be held at the **Charlottesville Omni Hotel on July 28th and 29th, 2006.**

Last year's conference, "Helping Our Children Get What They Need," was held at Germanna Community College in Fredericksburg, and according to our evaluations, presented information that was very helpful to families of children with mental, emotional and/or behavioral disorders, as well as the service providers who work with them. This year we are



looking forward to working with even more families, and we will cover the cost of attendance for a limited number of families. If you plan to attend, please call Medical Home Plus/VA INFO Center at (877) 264-8366 and ask to speak with the VA INFO conference registration coordinator.

VA FOF
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Spotlight On:

PARENT RESOURCE CENTERS

Judy Hudgins

Educator Representative on State Parent Resource Team

Parent Resource Center Specialist, Virginia Department of Education

Parent Resource Centers across Virginia provide invaluable support and training to families with children who have special health care needs. However, community support is essential to establishing and operating an effective Parent Resource Center. We encourage those who have an interest in improving the quality of life for children with special needs to learn more about Parent Resource Centers, the services they provide and opportunities for families and members of the community who can support their important work.

What types of services do the Centers offer?

All Parent Resource Centers provide:

- Direct assistance to parents - listening, giving information, providing resources, problem solving to enable parents to make informed decisions
- Training workshops for parents and educators, promoting active parent involvement and parent/professional partnership

Each Parent Resource Center determines what additional services to offer based on the needs of parents and the services available in the community. Other types of services provided by Centers can include:

- Providing initial contact with parents when their child is identified
- Organizing and/or facilitating parent-to-parent support groups
- Conducting surrogate parent training
- Publishing a newsletter
- Serving on interagency committees or councils
- Establishing a lending library and lending toy collection

Because Parent Resource Centers are supported by local school divisions, there are certain limitations in their activities. The staff of a Center serve as advocates for the child, working with parents to resolve concerns and problems. However, they may not serve as advocates for parents in formal mediation, complaints or due process proceedings. They refer parents to local or state advocacy organizations as needed.

What are the preliminary steps to starting a Center?

- Reviewing information regarding the Centers (available from the Department of Education) and visiting established Centers
- Administrative approval from the Superintendent, Board of Education, etc.
- Community support - Local Advisory Committee and other local leaders
- Advising the DOE of commitment
- Completing required forms for DOE assistance
- Selection of a parent of a child with disabilities and an educator to staff the Center

- Completion by the parent/educator team of the initial training

What type of training and assistance does the staff receive?

- Staff training continues throughout the first year, with additional staff development and technical assistance available in subsequent years.
- At the end of the initial training, the team is prepared to train other parents, work together effectively, open the Center, conduct a needs assessment in the community, assist in problem solving, plan and document the Center's activities, and model an effective parent/professional partnership.
- On-site technical assistance is available before and after the initial training, with small group and statewide in-service training scheduled during each year.

What are the major questions facing a new Parent Resource Center?

- Where can the Center be located to be accessible for parents?
- How is the Center to be furnished and equipped, especially with a direct phone line?
- How will the staff have direct access to the administration during the first critical months of operation?
- What are the needs of parents in the community and how will the needs assessments be conducted?
- Who are the key people, organizations and agencies in the community who need to be contacted personally?

For additional information, please call Judy Hudgins at (804) 371-7421.

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This is the Story of Amanda

Randy and Cathy Moran, Amanda's parents

We had one child and wanted another. However, having more children was not an option for us, so we applied for adoption. A few years later, we received a call from Social Services telling us about Amanda, a beautiful two-year-old who needed a family. The social worker said that Amanda was a healthy little girl with blonde hair and hazel eyes who had been placed in a foster home after being removed from a violent environment where drugs may have been used. The social worker stated that Amanda's birth mother denied using drugs and alcohol during her pregnancy.

Our social worker, Cathy, and I went to the foster home to meet Amanda. She came into the room wearing a little red and white dress, white tights and black shoes, and we knew after spending just a little while with her that we wanted to give her a home and a family that loved her. A month later, we welcomed Amanda into our family, just a few days before Christmas. What a gift!

About a year later, when the adoption process was finalized, we received a letter from the county outlining Amanda's past, her parents and the environment she had come from. To our astonishment, drugs and alcohol were in prevalent use during pregnancy. We were discouraged, but we loved Amanda and prayed she would be spared the harmful effects caused by her biological mother's abuses.

Today, Amanda is 19 years old. She lives in residential care, and has a diagnosis of:

- Schizoaffective Disorder, Bipolar type
- Cognitive Disorder
- Oppositional Defiant Disorder
- Fetal Alcohol Syndrome (FAS)

Once she began grade school, signs of social dysfunction became more apparent. Amanda did not have any friends, and she was withdrawn and very stubborn. Amanda began therapy with a child neurologist. Later, tests showed Amanda was delayed mentally and she

was diagnosed with ADHD. She was started on medication, her IEP was adjusted, and things seemed to be "normal".

When Amanda entered middle school, her mental condition worsened. She began hearing voices, became suicidal and psychotic episodes were more frequent. Amanda required hospitalization on several occasions and the hunt for the right psychotic medications began. Medications were a nightmare; she did not want to take them, and many had side effects such as weight gain. Amanda ballooned from 100 pounds to 175 pounds within six months. She was miserable, hated life, and wanted to die. Life as we knew it no longer existed. We were in a crisis and had no idea what to do. Our insurance was limited, co-payments were exceeding \$1,000 a month, and Amanda needed 24/7 residential care, which was not covered by insurance and we could not afford. We turned to God and to the county Social Service department from which we had adopted Amanda. The county offered us an adoption subsidy which covered any medical cost beyond what insurance would pay.

After a couple more admissions to the psychiatric hospital, Amanda was admitted to a residential care facility in Leesburg, which could not meet her needs. Amanda refused to take medications, became psychotic, suicidal and aggressive. She was expelled from the facility after a few months to an acute care facility near Washington D.C, and then to a residential care facility in Norfolk, where they did a phenomenal job treating her. Amanda was responding to treatment and was released to live at home. It was a great homecoming, but very short lived. Amanda stopped taking her medications and once again was admitted to a psychiatric hospital. At her request, Amanda was transferred back to the residential treatment center in Norfolk by ambulance.

Amanda went through periods of treatment compliance, then non-compliance. In time it became apparent that the Norfolk facility had done all it could, and the judge sent Amanda to a hospital

in Staunton, Virginia. They were able to stabilize Amanda, but could not provide long-term care which Amanda needed. Again, we contacted the county from which we had adopted Amanda. They had been receiving monthly progress reports and were aware of Amanda's needs. We were given a list of Virginia facilities that we should consider for Amanda. We contacted each residential care facility on the list, only to be denied admission, stating that the needed human resources to address Amanda's issues were not available.

Fortunately, the Staunton hospital recommended the Florida Institute of Neurological Rehabilitation (FINR), which accepted Amanda based on her FAS diagnoses. The county from which we had adopted Amanda was not supportive of this move because of the cost, but we had no options. Amanda was admitted to FINR under the county subsidy.

Since admission, Amanda has not had any reported psychotic episodes, she is attending high school, and is working on independent living skills. She doesn't like to take her medicines, but she does. She still does not take responsibility for her actions, and continues to make poor decisions because she doesn't have the cognitive ability to foresee consequences. Why does she take her medications now? The answer is FINR'S commitment to positive behavior reinforcement. If your behavior is acceptable and you comply with medication as prescribed, you earn shopping trips, lunch or dinner at a local restaurant, visits the beach, or other activities. FINR is an unlocked facility, the staff really wants to be there, and they like their jobs. Since Amanda is so far away, we visit her at least four times a year and talk to her almost daily.

Our dilemma is that Amanda's subsidy expires when she turns 21 years old. Cognitively, she is about 15. She requires 24/7 care, which we cannot provide. She often talks about coming home, not needing medications, driving a car, etc.... but without the medications she is not safe to herself or others. The

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Amanda...

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ultimate goal for Amanda would be for her to live independently with support services. However, to give Amanda time to mature and continue to learn independent living skills, it would be best if she could live in a group home setting here in Virginia. But such facilities are not available, nor is funding.

Our goal has always been to give Amanda the opportunity to enjoy life. It hurts that Mom and Dad can't fix this, but we need help. The thought that Amanda may end up in a state mental institution when other options should be available is overwhelming. She deserves adequate treatment for her illness, an illness that should not be discriminated against by lack of state and federal funding. Not knowing what to do next for our daughter, we will start looking into Medicaid waivers and hope she qualifies. Without some assistance, Amanda may not have the chance to overcome the disease that robbed her of her teen years.

New Approaches to Improving School Discipline

The issue of discipline in schools has long been a concern to administrators, parents and students alike. In the past, school personnel relied mostly on punishment, with the hope that this would eliminate the problem behavior. We now know that punishments such as out-of-school suspension don't really work, and in fact often make the problem worse.

Over the past 15 years, schools have developed better ways to respond to student discipline problems. By creating a standard set of school-wide and classroom-level student expectations, teaching students exactly what is expected of them, and rewarding positive behavior, we are significantly reducing behavior problems. This improves the climate of the school, enabling staff to focus on ways to

improve students' academic performance.

For the few students who still have behavior problems, teachers examine more closely the reason(s) behind the problem and deal individually with each student. Together, these approaches are changing Virginia schools and increasing the likelihood that all students will succeed in school and beyond.

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