



Family to Family Network of Virginia

Partnership for People with Disabilities @ VCU

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Why the Family to Family Network?

Laying the Groundwork...



The Value of Parent Connections

“Finally, someone understood what I was feeling because she’d felt this way, too. After I met Susan, I just started reconnecting to the world again. I thought I could do it because I could see that’d she done it herself. And that gave me hope.”

-- Sherri W.



Parent to Parent Support is not new

- ✧ 1st P2P – 1970 (Omaha, NE)
- ✧ 1st Virginia P2P – 1976 (Big Stone Gap)
- ✧ Parent to Parent of Virginia created by the Partnership for People with Disabilities in 1987 to support local P2P programs
- ✧ Efficacy Study of P2P Support (1990s) led to evidenced-based peer support

www.p2pusa.org



Center for Family Involvement

- ✧ Established in 2005
- ✧ Funded by Virginia Departments of Education and Health and the US Maternal & Child Health Bureau and Administration on Developmental Disabilities
- ✧ Offers
 - ✧ Indirect Support (PRC technical assistance, Collaborative IEP materials, Middle School Transition, Parent Summit)
 - ✧ Direct Support (Family to Family Network of VA)

www.centerforfamilyinvolvement.org



The Network provides:

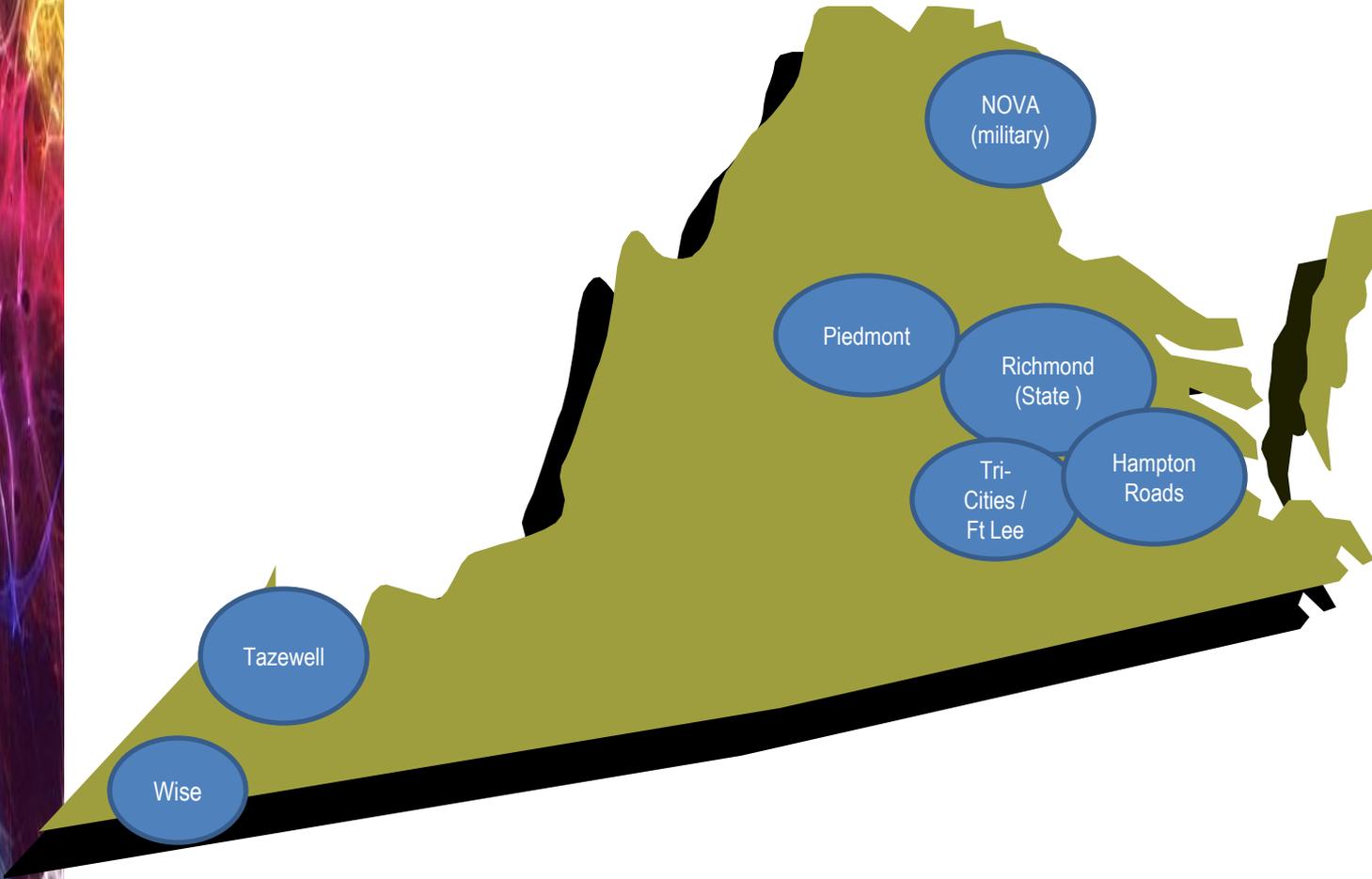
- ✧ Family friendly information and resource referrals
- ✧ A family assessment process to identify needs and form the basis of a plan designed to give families more control over their decisions and their lives;
- ✧ Parent to parent support; and
- ✧ Leadership development to support families in advocating for and participating in the design of more family-friendly, effective service systems.



Elements of Network

- ✧ Coordination of local Networks by paid parents who have participated in leadership training
- ✧ Support of trained, seasoned, open-minded volunteer parents (Family Navigators)
- ✧ Availability of cultural brokers
- ✧ Advice from Local Planning Team
- ✧ Maintenance of a database of family issues and needs

Local Networks



(877) 567-1122



Local Network Coordinators:

Central VA – Vicki Beatty

Hampton Roads – Joan Brunner

Northern VA – Charlie House

Piedmont – Tim and Jill Rose

Southside/Ft. Lee – Norma Draper

Southwest/Tazewell – Christy Worley

Southwest/Wise – Kerri Kochelek

Liaisons:

African American community – Mauretta Copeland

Latino community – Maria Isabel Frangenberg

Military community – Charlie House

Mental/Behavioral Health community – Vicki Hardy
Murrell



What we look for in Family Navigators

- ✧ Experiential knowledge of joys and challenges of raising a child with disabilities or special health care needs
- ✧ Sensitivity to the range of emotional responses that families experience
- ✧ Information about early intervention and educational program options
- ✧ Specialized parenting skills that emphasize meeting the unique needs of a child with disabilities or special health care needs
- ✧ Unbiased information about available options, services, supports
- ✧ Local, state, national resources
- ✧ Knowledge of the state disability services systems
- ✧ Formalized training from and on-going affiliation with Center for Family Involvement



Training for Family Navigators

12 hour initial training

- * Role as a mentor
- * Developing person-centered descriptions
- * Habits of successful collaborative teams
- * Private insurance
- * Military insurance
- * Medicaid
- * Medicaid Waivers
- * Negotiation skills in collaborative IEPs
- * Local, state, national resources

Monthly meetings with navigators:

- * social support
- * on-going training (supported decision-making, SSI, health care reform, etc.)
- * Local resources



Role of Family Navigators

- ✦ provide parents with the opportunity to **establish an emotionally supportive relationship** with an experienced parent of a child with a similar disability or special health care need.
- ✦ provide an **understanding of the unique needs** of children who have disabilities or special health care needs.



- ❖ provide **unbiased information** regarding available options, supports, and/or services.
- ❖ **link families to resources** available locally, regionally, and statewide.
- ❖ help families through **planning for service meetings** (IFSPs, IEPs, ISPs)
- ❖ ensure that **families' voices** are heard in the systems that are serving them.



Local Planning Teams

- ✦ Each Network has a local planning team comprised of local schools, public agencies, non-profits and parents
- ✦ Meet 3 times per year to discuss local needs and provide advice on Network activities
- ✦ Assist with Network outreach and recruitment of Family Navigators



What we have heard from families in Virginia

9 month snapshot

- ❄️ 1:1 support

 - ❄️ 285 families

 - ❄️ 110 professionals

- ❄️ Training

 - ❄️ 735 parents

 - ❄️ 575 professionals



What we have heard from families in Virginia

9 month snapshot

- * Autism 20%
- * Mental/Emotional/Behavioral 15%
- * ADD/ADHD 12%
- * ID 10%
- * Speech/Language 8%
- * Blind/VI 7% 50% white
- * Other Health Imp 7%
- * DD 4% 30% african american
- * Genetic 4%
- * Orthopedic 4% 10% hispanic
- * Multiple Disabilities 3%
- * LD 3%
- * TBI 2%
- * Deaf/HH 1%



Needs

- 1) Navigating/Accessing Systems (disability specific resources, support groups, recreational ideas)
- 2) Financing Services (IEPs, Medicaid Waivers, SSI)
- 3) Partnering in Decision-Making (communicating with teachers/providers, serving on SEACs, cultural competence)
- 4) Transition (guardianship, employment, college, housing)



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