

Families and Youth in the Driver's Seat

**Strategies for Partnering with and Engaging
Families And Youth**

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When any family has to navigate the system, these are often the words we relate to...



But, When Mental Health is Involved, Often Other Words Get Added...

Shame

Lost

Misunderstood

Blame

Helpless

Depression

Anger

Unworthy

Loss **Hopeless**

Stigma



Our Families and Youth Need a Voice!



- Have a different set of needs and experiences than families and adults affected by the adult mental health system and families with children and youth with special needs.
- Feel blamed and shamed. Stigma is very real and families and youth feel it all the time.
- Feel alone, isolated, helpless and hopeless.
- Want and need a place where their unique needs and voices are being heard and met. And, while other states have very strong and robust statewide family networks in their children's mental health systems, Virginia has never really been able to get its own network off the ground.
- An untapped source of leadership and support.



What is NAMI Virginia doing?

- NAMI Basics: 6 weeks education program for parents who have children with mental health needs, similar to Family to Family.
- Parents and Teachers as Allies: In service teacher training taught by parents on the needs of children and youth with mental health disorders.
- NAMI On-Campus: Clubs on college campuses that focus on promoting mental health awareness and giving a voice to students who have personal experience with mental illness.



What is NAMI Virginia doing?

- Started the Virginia Family Network June 2011 with the goal of developing a statewide network of parents with children and youth with mental health needs who provide support, education, and advocacy to other parents with similar experiences.
- In addition, started the Virginia Youth Leadership Network that includes developing youth groups that are facilitated by young adults with lived experience. Have hired a full time Youth Coordinator and have started a group in Richmond.



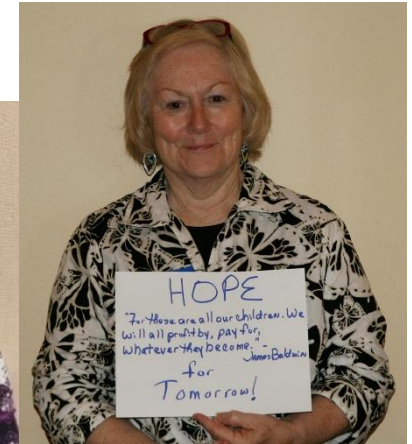
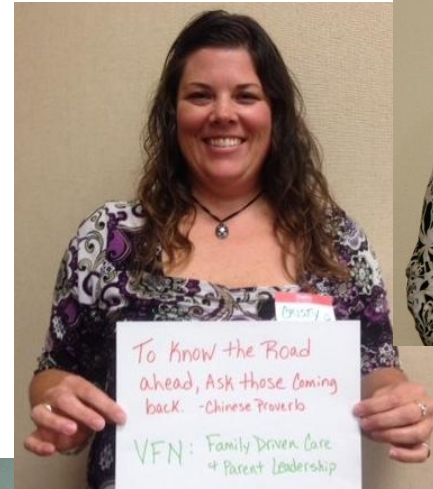
What is the Virginia Family Network?

- A grassroots network of families committed to providing opportunities that support, educate, and empower other families with children and youth with mental health needs while also promoting family driven and youth guided policy throughout the child serving systems
- Designed to “meet the family where they are” through activities such as providing support groups, training, resources, and mentorship from other families with children and youth with mental health needs
- A program of NAMI Virginia
- Supported through grants from DBHDS and SAMHSA
- ***Virginia’s Statewide Family Network***



What We Do For Parents

- **Support Groups** - We provide support and education for parents, and they are active in their communities to ensure that it is the families' needs and experiences that are driving the design and delivery of local services.
- **Trainings** – We offer a variety of trainings for parents that provide them with the skills they need to be advocates for their children and leaders in their communities.
- **Resources and Information** - We provide parents with resources and information to better educate them on the issues and experiences that may face.



What We Do For Youth

Virginia Youth Leadership Network

- **Support Groups** - We want youth to have a voice in their communities and to have the opportunity to get support from other youth. These groups will be led by the youth themselves (under the supervision of a youth facilitator) with the goal of supporting youth while empowering them to be advocates and leaders in their communities.
- **Trainings** - We will offer trainings that focus on the skills they need to be active participants in their own care and leaders in their communities.
- **Resources and Information** - And, of course, we want to provide youth with resources and information that are relevant to their needs and experiences.



VFN in Action

- Annual Statewide Family and Youth Leadership Summit in May, *Save the Date for May 3, 2014 in Richmond!*
- In September, held a statewide Advanced Parent Leadership training that focused on skills relevant to being a family partner and other leadership roles
- In November, held a statewide Youth Leadership Training the focused empowering youth and young adults to be leaders in their communities
- Offer a number of trainings for parents and professionals, including a day long advocacy training for parents, known as Driving the Care for your Family
- Help recruit parents to serve as parent representatives for FAPT, CPMT, and other committees
- We see ourselves as a “clearinghouse” for anyone doing family and youth support in Virginia. We are here to help!



Moving Towards a Family Driven and Youth Guided Approach



We've Come A Long Way...

- Lack of involvement and parents feeling blamed, tired, angry, and frustrated
- As a result, families started organizing and “meeting at the kitchen table” to find to support and advocate for other families
 - Family organizations formed – NAMI and Federation of Families for Children’s Mental Health
- Child and Adolescent Service System Programs –CASSP - began in 1983
- Starting in the 90s, Systems of Care began – introduced concept of care being child centered and family driven
- As family organizations and Systems of Care communities have become established, youth groups and youth organizations have organically started



The Way We Work with Family Has Changed...

- Control by professionals to partnership with families and youth
- Only professional services to natural supports
- Multiple case managers to one care coordinator
- Family blaming to family partnerships
- Deficits model to strengths model
- Mono cultural to cultural competence

Orrego, M. E. & Lazear, K. J. (1998) EQUIPO: Working as Partners to Strengthen Our Community



New Freedom Commission on Mental Health (2003)

Conducted a comprehensive study of the U.S. mental health service delivery system and make recommendations based on its findings.

The President's Commission found that:

- There is evidence that outcomes improve when family and youth *participate actively* in treatments
- Family and youth engagement and subsequent commitment to treatment are heightened when they have *leadership roles* in clinical decision-making.



Using a coordinated, collaborative family driven approach leads to positive outcomes (Systems of Care sites)

- 81% attending school regularly (20% reduction in absences)
- Juvenile arrests fell by more than half (from 27% to 11%)
- Reduction of 44% in suspensions and expulsions from
- 48% of youth showed improvement in emotional and behavioral health

Source: Sweeney, M (2013), Strategies for a Family-Driven Approach in Policy and Practice, Virginia Family Network Family and Youth Leadership Summit



Family and Youth Involvement at All Levels Leads to Better Outcomes

- Families and youth *know what works* for them
- Families and youth *know their limitations*
- Families and youth *keep track of services and change*
- Family and youth's level of *comfort and trust are necessary for success*



Inclusion of family driven and youth guided care in the service array

- Multiple states now have legislation requiring family involvement, peer support, system of care and wraparound services
- Medicaid provides funding for peer and family support through state plan amendments (7 states) or Medicaid waivers (6 states) or both (1 state) – others are considering options for funding peer/family support
- Certification available in several states (TN, NY, others) and nationally (Certified Parent Support Provider)
- Local Systems of Care grants required youth involvement resulting in Youth Coordinator and Youth Peer Support Specialist positions



May 2013 memo from CMS

Designed to provide guidance to states on how to design a benefit package to cover children/youth with significant mental health issues.

- includes “intensive care coordination (often called wraparound service planning/facilitation), family and youth peer support services, intensive in-home services, respite care, mobile crisis response and stabilization, and flex funds.”
- "States have significant flexibilities in the Medicaid program to cover mental health and substance use services for youth with significant mental health conditions."
<http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-05-07-2013.pdf>



The Roles of Families and Youth in Systems have Evolved

As Collaborators:

- Families share equally with all others in the system in planning and doing the work, reaping the benefits, and resolving the challenges that arise
- Professionals are beginning to really collaborate with caregivers rather than “serving” them as “clients”

As Advisors and Advocates:

- Advocacy at the individual, group, policymaking and system levels
- Seeing a shift in attitude, from “you just happen to be a parent” to “you have an expertise that no one else has”



The Roles of Families and Youth in Systems have Evolved

As Peer Support:

- Families raising children with emotional and behavioral disorders often feel isolated, frustrated and stressed – the need for peer support is what brought families together in the first place
- Caregivers provide effective support for other caregivers because they have experienced many of the same emotions and struggles – respite, support groups, etc.



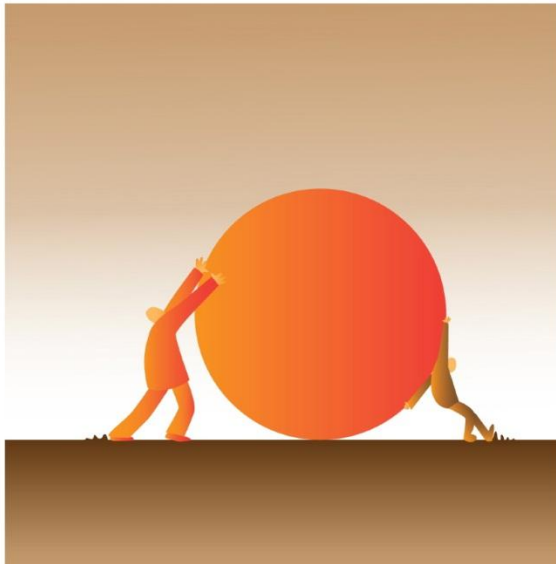
The Roles of Families and Youth in Systems have Evolved

As Service Providers:

- Family members are being trained to do more than advocate and advise, especially in family-run organizations
- Family members are beginning to make administrative decisions and take on leadership roles in service delivery systems; taking positions that were traditionally only for professionals and degreed persons
- Providing direct services in multiple settings: mental health centers, pediatrician offices, health departments, schools, juvenile courts, child welfare offices



**Becoming more family
driven and youth guided
at all levels may be
harder than you think...**



Why?



Because we have to shift the way we provide services...

We have to move from a traditional approach (medical model) to a family driven, youth guided approach with family and youth as equal partners at all levels.



Family Driven

Families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children.

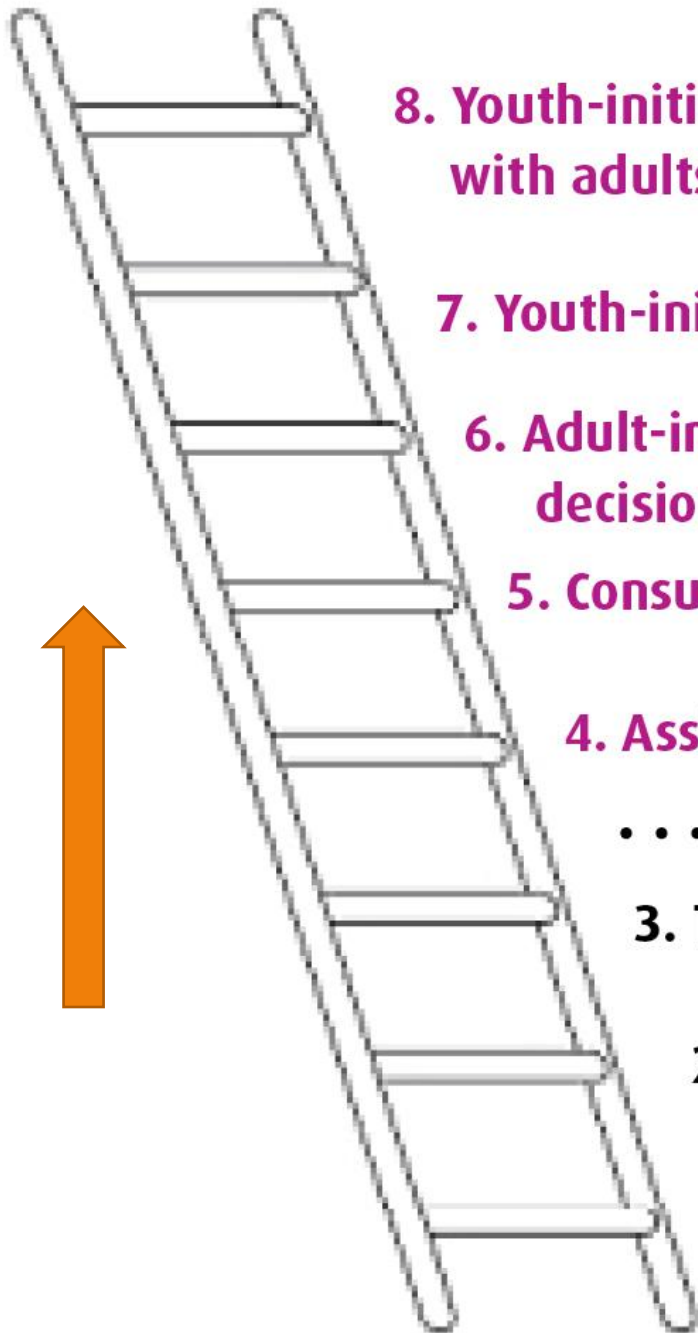
Family Engagement

The community has an active effort underway at some level to engage families in parts of the system of care. Overall impact that families have on the system, plans, and implementation is not yet significant.

Family Involvement

Families are included or participate in some parts of the system; although only in positions considered to be traditional or “safe”. Family involvement at this level is not in significant places, positions, or numbers.





8. Youth-initiated, shared decision with adults

7. Youth-initiated and directed

6. Adult-initiated, shared decisions with youth

5. Consulted and informed

4. Assigned but informed

3. Tokenism

2. Decoration

1. Manipulation

Ladder of Youth Participation

<http://www.waggstalkingactionongender.org/youth-participation-2/how-young-people-participate/the-ladder-of-participation/>



What is Family Driven Care?



- Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:
 - Choosing culturally and linguistically competent supports, services, and providers;
 - Setting goals;
 - Designing, implementing and evaluating programs;
 - Monitoring outcomes; and
 - Partnering in funding decisions.



10 Guiding Principles of Family Driven Care

- 1) Families and youth, providers and administrators *embrace the concept of sharing decision-making and responsibility* for outcomes.
- 2) Families and youth are *given accurate, understandable, and complete information*
- 3) All children, youth, and families have a biological, adoptive, foster, or surrogate *family voice advocating on their behalf*
- 4) Families and family-run organizations *engage in peer support activities*
- 5) Families and family-run organizations *provide direction for decisions that impact funding*



10 Guiding Principles of Family Driven Care

- 6) Providers *take the initiative to change policy and practice* from provider-driven to family-driven.
- 7) Administrators *allocate staff, training, support and resources to make family-driven practice work* at the point where services and supports are delivered
- 8) Community attitude change *efforts focus on removing barriers and discrimination* created by stigma.
- 9) Communities and private agencies *embrace, value, and celebrate the diverse cultures* of their children, youth, and families
- 10) Everyone who connects with children, youth, and families *continually advances their own cultural and linguistic responsiveness*



What is Youth Guided Care?

- **Youth Guided** means that young people have the right to be **empowered, educated**, and given a decision making role in the care of their own lives as well as the policies and procedures governing care for all youth in the community, state and nation.
- This includes giving young people a **sustainable voice and then listening to that voice**.
- Youth guided organizations create safe environments that enable young people to gain self **sustainability** in accordance with the cultures and beliefs with which they identify.
- Further, a youth guided approach recognizes that there is a continuum of **power** that should be shared with young people based on their understanding and maturity in a **strength based change process**. Youth guided organizations recognize that this process should be **fun** and **worthwhile**.



Being Family Driven and Youth Guided at All Levels:

- Policies
- Procedures
- Processes
- Planning
- Service implementation



Being Family Driven and in Policy and Procedure

- All policies should be accessible to families and youth for review and feedback
 - Policies and written procedures should use *inclusive* rather than *exclusive* wording
 - Develop an ad hoc committee of family members and youth receiving services to review your policies and suggest changes – USE their feedback!
- Develop policies/procedures that employ family driven care principles
 - Clear implementation in daily operation of program or agency
 - *Examples:* How is your wait list set up? How are the phones answered in your office?



Being Family Driven and in Policy and Procedure

- Involve families in development and review of program or agency policy and procedures
 - Ask family members for feedback on your forms and service paperwork, experience with calling your office or making appointments, etc.
- Incorporate family members (and youth!) as voting members on your board or governing body
- Include families as key members of workgroups, advisory boards, etc. to assist in decision making
- Empower family members to take active roles as legislative advocates to positively affect local and state policy making



Being Family Driven in Program Management

- Use caregivers and youth as Co-Trainers in training activities and presentations (internal, external)
- Incorporate service recipients as advisors in the hiring of personnel
- Incorporate family members in designing and implementing programs, providing feedback on grant proposals, and assisting in needs assessments
- Incorporate family members as an active part of quality improvement process and monitoring outcomes (i.e., care review team, evaluation)
- Caregivers and youth can be helpful in determining the effectiveness of all efforts to promote the mental health and well-being of children and youth



Being Youth Guided in Policy, Procedure, and Program Management

- Promote an organizational culture that sees youth participation as valuable and feasible
- Ensure youth are present when decisions that impact them are made, from individual service delivery to program development to policies/procedures – HEAR and USE their feedback
- Help prepare youth for active participation – training on purpose of policy making committees, advocating effectively, etc.
- Review agendas prior to meetings to allow youth real opportunity to think about what and how they want to contribute to topics on the agenda
- Learn to talk in ways that don't alienate youth
- Develop a welcoming, safe environment for youth involvement and participation



Some Examples of Family Driven and Youth Guided Care in Virginia

- Horizon Behavioral Health (Lynchburg's CSB) has its own parent support resource center where families can get individual parent to parent support and resources
- Loudon County has formed a parent organization where families can also get support and resources while ensuring that services are family driven and youth guided
- UMFS has hired a part time family partner for its residential program
- Colonial Behavioral Health (Williamsburg CSB) hosted a parent conference in April
- Virginia Beach CSB has a family educator that facilitates a monthly parent support group and other educational programming
- Rappahanock CSB distributed a survey to its parents to assess its services, ability to engage families, families support needs, etc
- Alexandria CSB is hiring a full time Youth Coordinator



Hiring Caregivers – Strengthening Service Delivery

Caregivers can play many roles, infusing family voice at all levels of service delivery:

- Care Coordinators
- Family Support Partners (peer support)
- Peer Supervisors
- Trainers
- Evaluators
- CQI/QA
- Child and Family Team Facilitators
- Support Group Facilitators

Youth can fill many of these roles, too!



Family members as change agents

- A nationally growing profession, known as parent peer support (aka family partners, parent partners, family support specialists, etc.)
- Caregivers hired to work with other families
 - Based on life experience, not degree
 - Peer to peer support that facilitates effective service connection and delivery
 - Modeling of advocacy and collaboration skills



Roles for Youth – Promoting Youth Involvement

- Youth group facilitation
- Peer advocates
- Educators/Trainers
- Youth representatives on committees, boards, etc.
- Social marketing
- Evaluation
- Decision making, leading, organizing



Roles for Youth Coordinator – Growing Profession

- Full time position (ideally)
- Coordinate and foster local youth efforts
- Mentor/coach/support other youth
- Lead a youth group
- Raise awareness and educate the important of the youth voice and youth guided care
- Promote youth and adult partnerships



Engaging and Partnering with Families and Youth

How can we support and engage families and youth?



We have them in the door...



philipmartin.info

Now, what??



You have to understand the journey families take...

- Every family's journey is different, but there are similarities and common feelings and reactions
- Common Stages
 - Shock/Denial/Disbelief
 - Recognition/Acceptance/Loss
 - Coping/Adaption
 - Advocacy

Adapted from NAMI Family to Family Education Program



“The Family Journey”

- Each family member experiences his/her own journey, and each family member needs support
- The family as a whole has its own journey
- The family journey is not linear – Family members can go back and forth through the stages and always need support
- The family’s culture can play a significant role in the family’s journey



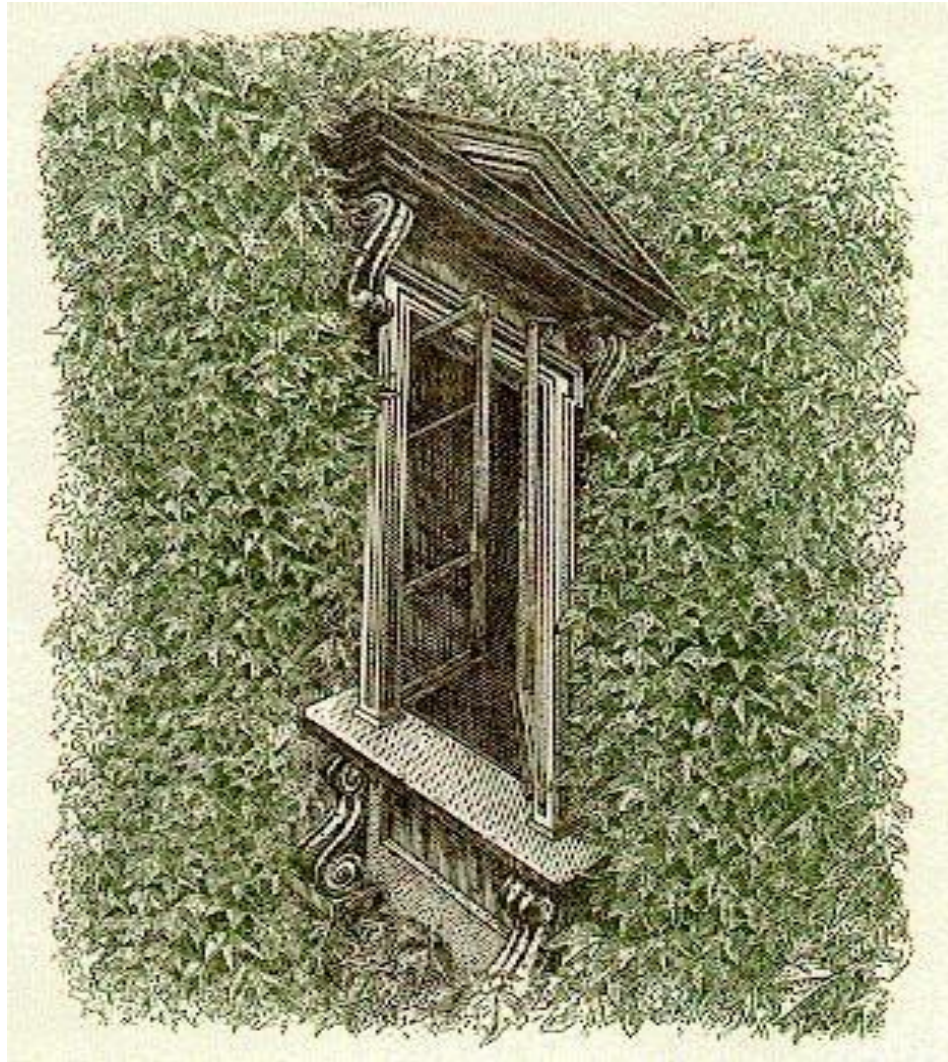


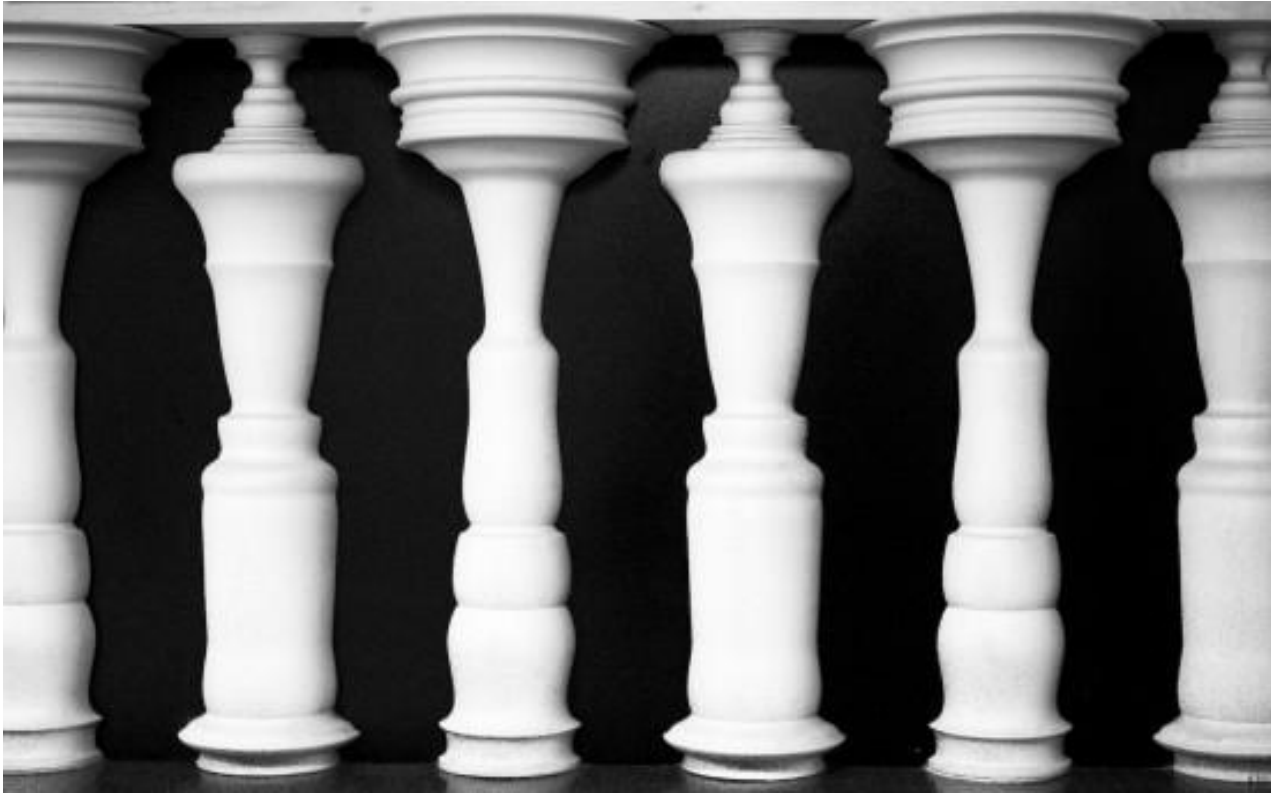
Perspective- taking is critical!

What is “perspective”?

- A particular attitude toward or way of regarding something
- A mental view or outlook
- Subjective evaluation of relative significance; a point of view
- A way of regarding situations, facts, etc. and judging their relative importance







A basic fact: Families and professionals view “at risk” children/youth in different ways.

- An educator sees a *student* in danger of dropping out
- A juvenile justice staff sees a *potential runaway or delinquent*
- A clinician sees a *client* with mental health issues
- A community leader sees the *troubled offspring* of a community resident
- A family member sees a *sister, brother, daughter or son* who has unique needs



**Families see their children as
people first.**

Their special needs come *second*.



**This is what makes family and youth
involvement *unique* and a *critical* component to
any service system or service delivery.**



In addition to perspectives...

- *Our systems operate under a deficit based system*
 - We are set up to look at what is NOT there, rather than the strengths that ARE present
 - Assessments usually based on deficits and what is wrong
- *Traditional training does not focus on family driven care and parent involvement or leadership*
 - Training is usually based on a medical or professional model
 - Learn to “do to” families rather than “do with” families
- *Assumptions we make about families and each other*



Elements of disconnect

- Unrealistic expectations
- Unacknowledged emotions
- Unmet Needs
- Unclear roles
- ***Unspoken assumptions***



Four historical views of parents

(these are based on assumptions!)

1). **Parent as an Obstacle**

A view based on the notion that if the parents would get out of the way, the child would get better.

2). **Parent as an Object of Pity**

A view that emphasizes what parents cannot do, rather than what they can.

3). **Parent as an Object of Education**

A view in which parents are treated as if they have deficits that require training or re-education.

4). **Parent as a Disinterested Party**

A view in which the professionals feel as if they have a stronger investment in the child's well-being than does the parent.



Professionals have unspoken assumptions about parents:

- They don't understand the limitations of my job/the system.
- They don't really want to try something new to make this situation better.
- They don't respect the work I do.
- They don't know how to parent effectively.
- They don't really care about the child.
- They have a mental illness, too—that's where the kid gets it.
- They don't see me as a real member of their team.



Professionals have unspoken assumptions about youth:

- They don't understand the limitations of my job/the system.
- They don't really want to try something new to make this situation better.
- They can't make any decisions for themselves.
- They can't be leaders or take care of themselves.
- They don't really care about themselves.
- They don't see me as a real member of their team.



Parents and youth have unspoken assumptions about professionals:

- They don't listen to my opinions.
- Their decisions are made before I even get to the meeting.
- They don't respect me.
- They think I'm a bad parent.
- They blame me for my child's behavior.
- They don't understand what it's like at home.
- They don't realize I have other kids in the house who need things.
- They don't realize I'm overwhelmed.
- They don't see me as a real member of the team.



Where do these assumptions come from?

- By definition, an assumption is something you think is true but may not be backed by any facts or that may be related to your own emotion about something or someone
- We make assumptions when
 - We have had negative experiences in similar situations in the past
 - We lack all of the information we need
 - We are anxious, afraid, angry, overwhelmed
 - We find ourselves in uncomfortable or unfamiliar situations
 - We fall back on labels, titles, biases, and prejudices rather than having an open mind



Remember...

Family perspective is based on a family's experience with their child and an understanding of their child's strengths, needs, community, and culture.

Youth perspective is based on the youth's lived experiences and priorities

Professional perspective is based on training, cumulative clinical experience, and the ability to listen carefully and respectfully to others.



Parents want to feel.....

- Valued
- Listened to and heard
- Less guilt, less blamed
- Confident
- Knowledgeable
- Proactive (vs. Reactive)
- Assertive (vs. Aggressive)
- Informed
- Involved/included in a meaningful way
- That they are regarded as an expert on their child's strengths and needs
- Hopeful for their child's future



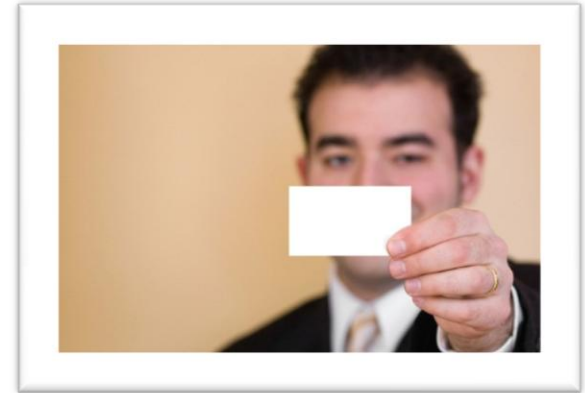
Youth want to feel.....

- Valued
- Listened to and heard
- Less guilt, less blame
- Confident
- Knowledgeable
- Proactive (vs. Reactive)
- Assertive (vs. Aggressive)
- Informed
- Involved/included in a meaningful way
- That they are regarded as the expert on their own care
- Hopeful for their future



And...Professionals want to feel...

- Valued
- Listened to and heard
- Less guilt, less blamed
- Confident
- Knowledgeable
- Proactive (vs. Reactive)
- Assertive (vs. Aggressive)
- Informed
- Involved/included in a meaningful way
- That they are regarded as an expert in their field and able to contribute something positive to your situation
- Hopeful for the child's future



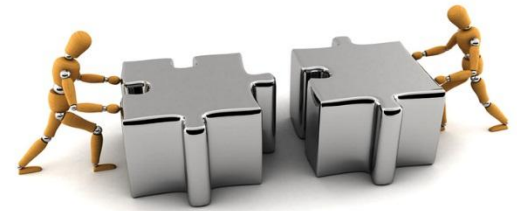
So we have a bit more in common than we thought...



We both want children and youth to be successful but have different roles in achieving that goal.



**There is common ground
to work from.....**



***And this is where parent leaders
operate in their communities!***



The Family Journey as a Guide

- Focus on impact - How is he/she thinking and feeling right now; how is he/she coping
- Encourage parents to describe their experiences as they see it – “I am not here to judge”
- Be fully attentive – Simply, listening can go a long way
- Approach with acceptance, rather than blame
 - Parents are the experts on their child’s care
- Utilize a wide array of engagement skills – Be creative
 - For example, can you meet outside the office?



The Family Journey as a Guide

- Provide validation, perspective, and guidance on what is going on in his/her life
- Connect parents with other parents – They can provide support, share resources, and reduce isolation
- Set a framework for solutions and hope
- Communicate empathy
- Acknowledge that life is chaotic and this affects families reactions and abilities to cope and remember that you are able to go home and get a break from the chaos



The Family Journey as a Guide

- Ask questions to understand culture, identity, and experiences
- Be honest with families in terms of what you are able to provide
- Set clear expectations and make sure the family is on the same page as you throughout the process
- Acknowledge that families are going through a grieving process
- Empower families to be their own advocates – Help them identify their strengths and needs



Partnering with Youth

- Compensate them for their time, ie as youth representatives at meetings, forums, speaking events, etc.
- Youth friendly meeting times
- Share resources
- Provide training
- Start a youth group (*we can help!*)
- Be honest, set clear expectations, and clarify your limitations
- Scholarship youth for conferences (ie Georgetown Training Institutes Youth Track)



Moving Forward

*How Can YOU Promote
Family Driven and Youth
Guided Care?*



Being Family Driven and Youth Guided in Your Specific Role

What is your role?

- Caregiver
- Youth
- Provider
- Advocate
- Educator
- Policy Maker

Given your specific responsibilities, how you can implement family driven, youth guided care?



Getting Started

- Build on what you have – program outcomes, training curriculum, policies, strong cadre of parents/parent partners (i.e., CSA services, incl. child/family teams)
- Know requirements of your Medicaid waiver and legislation (i.e., CSA) – what’s covered, what is required regarding consumer and family involvement, how changes are made
- Consider if you need a certification or credentialing process for parent professionals
- Analyze where you are in implementation of family driven policies, procedures, or requirements at the local and state levels



Your Action Plan

Plan of Action: Becoming more family driven

GOAL: Promote family driven care in:

<input type="checkbox"/> Policy	<input type="checkbox"/> Service Design/Development	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Procedures	<input type="checkbox"/> Service Implementation	
<input type="checkbox"/> Processes	<input type="checkbox"/> Family/youth choice	
<input type="checkbox"/> Planning/Evaluation	<input type="checkbox"/> Interactions with others/modeling	

Action Step	Timeline	Outcome
1)		
2)		
3)		
4)		
5)		

Potential barrier(s) when implementing this goal:

Plan to address this barrier(s):

Identify your goals



What action steps do you need to take in order to meet your goals?



What are the potential barriers and how do you plan to address them?



Finding Parent and Youth Leaders

They are out there and ready to get started!

They want to use their own experiences to help other families and youth!

- Look at families and youth who are no longer clients and are doing well
- Check with schools
- Ask other staff (ie CSA, CSB, DSS workers, private providers, therapists, etc.)
- Ask us (ie VFN) for help – we can reach out to other families and youth and spread the word through our outlets
- Host family and youth events and trainings – We can provide the training!
- All you need is one young adult and one parent who is excited and eager to help!



State Resources

- Virginia Family Network – www.namivirginia.org/programs/Virginia-family-network
- Campaign for Children’s Mental Health – www.1in5kids.org
- FAVY (family organization for families involved with DJJ) - <http://www.favyouth.org/>
- FACES (family organization for foster and adoptive families) – www.facesofvirginia.org



State Resources

- Children's Mental Health Resource Center – www.mentalhealth4kids.org
- Formed Families Forward (family organization in Northern VA for foster and adoptive families)– www.formedfamiliesforward.org
- PEATC (special ed) - <http://www.peatc.org/>
- Center for Family Involvement (support for families with children with special needs) <http://www.centerforfamilyinvolvement.org/>



National Resources

- NAMI Child and Adolescent Action Center
http://www.nami.org/Template.cfm?Section=Child_and_Teen_Support&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=72&ContentID=38391
- Federation of Families for Children's Mental Health – www.ffcmh.org
 - National Certification <https://www.ffcmh.org/certification/resources>
- FREDLA – www.fredla.org/
- Youth Move National (Youth Resources) – www.youthmovenational.org
- Transitions RTC - <http://labs.umassmed.edu/transitionsRTC/>
- Pathways to Positive Futures RTC-
<http://www.pathwaysrtc.pdx.edu/>
- Child Mind Institute – www.childmind.org
- Children's Mental Health Network – www.cmhnetwork.org



For More Information...

We Are
Here to
Help!

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www.namivirginia.org/programs/virginia-family-network

www.namivirginia.org/programs/virginia-youth-leadership-network



Thank You!

