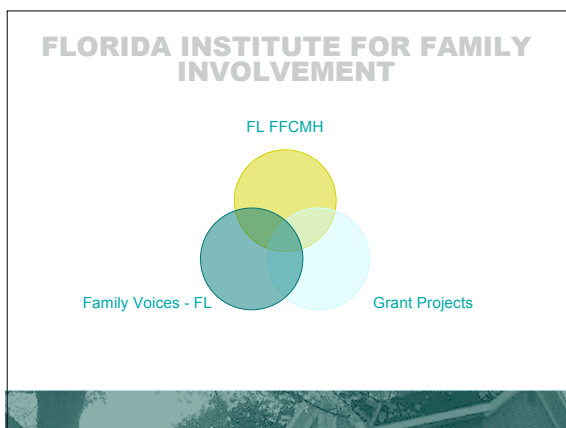


Who we are...

- a non-profit family run organization with a 501C3 status for the purpose of enhancing, facilitating, and supporting family and consumer involvement in the development of responsive, family centered, and community based systems of care.



What we do...

- Strengthen partnerships
- Foster family centered systems of care
- Creating leaders
- Sharing information

Who we represent...

- *Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.*

(Maternal and Child Health Bureau – MCHB)

How we are funded...

- Substance Abuse & Mental Health Services Administration
- Maternal and Child Health Bureau
- Contracts

Why we believe in the voice of families...



What is an “Authentic” Voice

- An authentic voice is one that represents the perception of families of children served by the system and results in views that are not coerced or shaped by anyone other than the families themselves.

How an Authentic Voice Can Be Used

- Program Development
- Program Evaluation
- Provider Selection
- Contract Management
- System Advocacy
- Reality Check

Garnering the Authentic Voice

- Finding families
- Listening to families
- Documenting their perceptions
- Sharing their voice

Finding Families

- Authentic Checkpoints
- Cultural representative of population served
- Service population representatives

Listening to Families

- Setting the stage
- Creating an environment of comfort
- Managing conversations
- Using family leaders

Documenting Perceptions

- Factual and actual
- No interpreting
- Do not make assumptions
- Creating a perceptual picture

Sharing their Voice

- Family driven use
- Families first
- Creative modalities
- Media
- Legislature
- Policy development
- Reinforcement of need

Packaging

- Family stories
- Story bank
- Data
- Quotes
- Photos
- Video

FIFI/FFFCMH Harvest of Family Voice

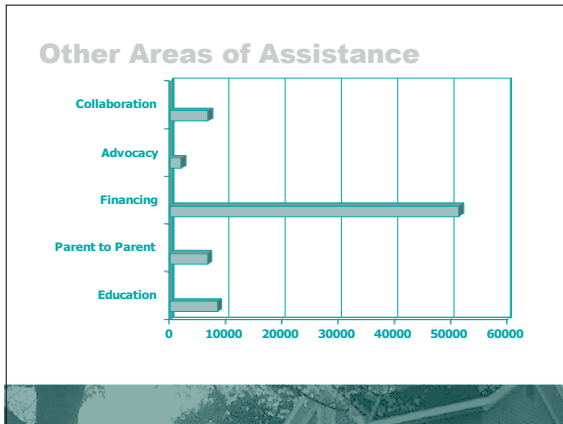
- Encounter Data
- Voice of Families Surveys
- Family/Youth Forums/Focus Groups
- Story Banks

Encounter Data

- Collection of basic data on calls and requests for assistance and information
- Can contribute to data required by funders
- Justifies or validates the efforts of the organization
- Helps prioritize issues and narrow focus

Requesting Assistance for Mental Health





OUTREACH

- Website Hits: 303,268
- Listserv Participants: 5465
- Presentations: 184
- Participants: 50,171

What This Told Us

- Major need among families if how to finance their care
- Families need parent to parent support
- Families still struggle with the education of their child
- People searching for information are using the internet

How We Used the Information

- Funding justification
- Prioritizing legislative advocacy
- Building the website
- Looking for outside funding for specific activities (building partnerships)

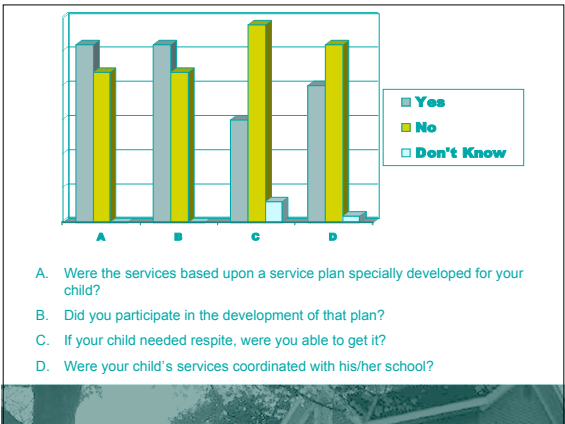
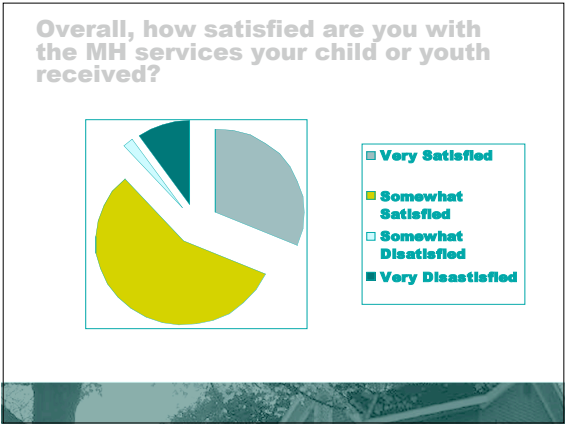
Voice of Families Survey

- Based upon statute and federal funding requirements for state use of dollars
- Integrates questions from the national CSHCN Survey for comparison
- Gathered throughout the year and analyzed once a year
- Can be done individually, verbally, or by internet

Sample Questions

Your zip code _____

	Never	Sometimes	Usually	Always	Don't Know
How often did your child's pediatrician screen your child for his or her mental health needs?					
Have your child's mental health providers talked with you about how his/her mental health needs might change when he/she becomes an adult?					
How often were the strengths of your child and family discussed when planning services for your child?					
How often were the needs of your entire family discussed and addressed when planning services for your child?					
How often have you been invited to help develop policy and programs for other families like yours?					
How often did your mental health providers make you feel like a partner in your child's care?					
How often were your mental health providers sensitive to your family's values and customs?					
How often did mental health providers share information about other community services and programs with you?					



What This Told Us

- How families perceived the system and the services they received
- How families interpreted the efforts of their provider network
- What families felt were missing in their system of care
- Specifics related to system of care impact and perceptions

How We Used the Information

- Validation of family needs
- Promoting family priorities with policymakers
- Numbers for advocacy efforts
- Better understand what FIFI/FFCMH needed to do to better prepare families as they navigate the system of care

Family/Youth Forums and Focus Groups

- Gatherings with structures but informal conversations about the system of care
- Guided questions to solicit positive and negative input
 - What do you like best about the services your child is receiving?
 - What is most frustrating about the services and the system of care?
 - If you had a magic wand and could change anything...what would you do?

What This Told Us

- Families had more positive than negative to say
- Most families will carefully detail what works and what does not work
- Answers change as the years change
- Families have INCREDIBLE ideas to create a family driven system of care

How We Used the Information

- Antidotal data
- Quotes for training
- Ideas on how families would like to change the system
- Prioritizing systems transformation according to the timetable of the families we work with

Using Quotes

"We all knew she needed help. They said she didn't meet their criteria...she needed a mental health diagnosis. By the time she gets that bad we won't need their help. Everything our family has fought for will be gone."

Parent

"I know that people do not like me. Sometimes I don't like me either, but I am all I got."

Seventeen year old with serious emotional disturbance

"Just getting up in the morning and coming to school is a major accomplishment for him. I wish the teachers would grade him on that effort."

School Administrator

Story Bank

- Collecting family "stories"
- Gather both good and bad and a few really ugly stories
- Maintaining stories in a data bank

Sample Story

- M.S Daytona Beach
The family has a child with special needs and received notification that their Kidcare was being cancelled. The family sent in all of her renewal information but still received a termination letter. They have tried to call Healthy Kids but were unable to get through several times and was put on hold for an hour another time.

What This Told Us

- What is happening today to the families of FL
- How systems change is impacting families and their ability to access necessary services
- What the "real life" perception is

How We Used the Information

- Shared with media for stories regarding systems change and financing
- Quotes for training
- Developed "story books" for legislative session
- Used stories to emphasize critical points of need
- Shared with each professional encounter

NOT WITHOUT RISK...

- The family voice can be powerful
- The reality can impact political directions
- The truth can make some leaders look bad
- Retaliation is a real threat
- Loss of partnerships can result
- Loss of funding becomes a major concern

What Is Next?

- Family Policy Academy
- Partnering with other organizations on story banking
- Legislative proposals to cut critical programs
- Congressional funding of services



"...if we wait for the moment when everything,
absolutely everything is ready, we shall never
begin."
Ivan Turgenev