“If citizens are to participate in the development of policy decisions that affect their own lives, the standard practitioner-client model must give way to a more democratic relationship between them.” (Frank Fisher)
CONCEPT

- Family – “Families are big, small, extended, nuclear, blended, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, fostering, adoption, marriage, or from a desire for mutual support. Together, our families create our neighborhoods and communities.”(Pediatric Care Online, 2008).
DEFINITIONS

- Engagement – 3(b). emotional involvement or commitment; 4. the state of being in gear (Merriam-Webster)

- Authentic – 1. not false or copied; genuine; real 2. having the origin supported by unquestionable evidence (dictionary.reference)
HISTORICAL PERSPECTIVE
AN EVOLVING ROLE

1900’s
Family members not involved in child’s treatment. Very likely to be blamed for the child’s “affliction”

1960 – 1970’s
Families of children with intellectual disabilities began advocating for increased family participation, legislation began to mandate family participation

1980’s
Mental health processonals began to question blaming families and a collaborative spirit of working together began to emerge

1990’s
Systems of care envisioned to offer services based upon the strengths of the child and family. Collaboration became a primary goal.

2000’s
Emergence of Family Driven Support
THE ROTATION OF POWER
Families and youth are given accurate, understandable and complete information necessary to set goals and make choices for improved planning for individual children and their families.

Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes.

Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation.
Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information and strengthen the family voice.

Families and family-run organizations provide direction for decisions that impact funding for services, treatments and supports.

Providers take the initiative to change practice from provider-driven to family-driven.

Community attitude change efforts focus on removing barriers and discrimination created by stigma.
• Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth and families.

• Communities embrace, value and celebrate the diverse cultures of their children, youth and families.

• Everyone who connects with children, youth and families continually advances their own cultural and linguistic responsiveness as the population served changes. (Osher, et al, 2006)
KEY WORDS FROM THE PRINCIPLES

01 Shared information
02 Shared decision-making and responsibility
03 Reduced isolation
04 Remove barriers and discrimination created by stigma
05 Embrace, value and celebrate diversity
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 supports, service and providers; setting goals; designing and implementing programs; monitoring outcomes; participating in funding decisions; and determining the effectiveness of all efforts to promote the mental health and well being of children and youth. (Osher, Osher, and Blau, 2006)
“Family-driven” does not mean “my way or the highway“. For this process to be successful, everyone must be willing to listen actively, strive for clarification, and be willing to compromise on behalf of the best interest of the child.
DEVELOPMENTAL MILESTONES

As a child matures, so must the family and the systems that are supporting them. Here are the broad definitions of three, important concepts.

Family-Driven: The family plays a major role in the decision making process about services and supports and serves as an equal member of the team.

Youth-Guided: As the child matures, their input into the decision making process grows.

Person Centered: As the child transitions into young adulthood, they become the decision maker about the services and supports they desire. These young adults may select to have their families continue to be a part of the decision making process and they receive counsel from all team members. These young adults are on the path to self determination.
SUCCESSFUL TEAMS...

...are fully-focused on the child and their family and are engaged in a developmentally appropriate fashion.
WHY ENGAGE FAMILIES?

- Professionals come and go in a child’s life. The family is the only true constant. Family engagement helps to establish sustainable practices and provides a sense of stability for the child.
HOW DO WE ENGAGE FAMILIES?

**Start**
- Start at the beginning. Strive to create a balanced relationship at the initial meeting.

**Acknowledge**
- Be gracious and acknowledge that you are the newcomer.

**Deliberate**
- Be deliberate about your intention to meaningfully engage families rather than to simply have them participate.
Ensure maximum **cultural humility**. Be appreciative and nonjudgmental of the family’s culture, ethnicity, religion and lifestyle.

Create welcoming environments. Child care, flexible meeting times, and transportation assistance are tangible examples of supports that may encourage engagement.
Feelings of blame and disrespect
Feelings of isolation due to lack of information
Feelings of intimidation
Feelings of being outnumbered
Feelings of incompetence due to not knowing the jargon
FEELING THAT THIS PROCESS IS IRRELEVANT TO THEIR LIVES

WHY FAMILIES ARE HESITANT TO ENGAGE
Information is power and professionals often overlook the significant amount of very important information that they do not have access to without the family’s input.

Families often disregard the important information that professionals possess about best practices.
Yes, it’s true. We sometimes appear very intimidating to children and families. Strategies to create comfort include:

- Meet with families in mutually comfortable locations. You may have a lovely office but if I have had bad experiences in your building, I’m not comfortable

- EVERYONE should be on a first name basis. Refrain from beginning a conversation with “Hello, I’m Dr. Smith”.
Power is a fluid dynamic and is often in the eyes of the beholder. Mistrust is also a two-way street. Families have had experiences that cause them to be wary of professionals, no matter how sincere they appear to be. Professionals often regard families with apprehension, based upon past, unsuccessful interactions.
WHY ARE WE HESITANT TO ENGAGE FAMILIES?

WAIT BUT WHY
HOW DO WE RESOLVE THIS?

Simply stating “treat families with respect and quit blaming them” is trite. It’s through the genuine acknowledgement of the expertise that families bring to the table that we begin to erase blame and disrespect.

Through the practice of balanced relationships we become a team with a mutual goal.
CHANGE THE SEATING ARRANGEMENT

From this

To this
Upon further discussion, most families will agree that it’s not the number of professionals in the room, it’s the demeanor of the group.

By making families feel truly welcome and appreciated, a feeling of comradery will develop and the number of professionals in the room will become much less important than the contributions of each team member.
Expertise:

Who has a better understanding of the cutting edge services and supports that are available than the professionals who have dedicated their lives to improving outcomes for children?

Expertise:

Who knows better which strategies have the best chance of success than a person raising a child with behavioral challenges?
FINAL THOUGHTS
THAT BEAR
REPEATING...

- Teams must be truly holistic and consider all aspects of the child and family’s life.
- Families must be sincere about the value that professionals bring to the table.
- Professionals must value the family’s expertise about their child.