

PARTNERING WITH FAMILIES TO IMPROVE QUALITY IN DEVELOPMENTAL DISABILITY SUPPORTS

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LIGAS FAMILY ADVOCATE PROGRAM**

GOALS FOR TODAY

1. **Explore the basic tenets of Family-Centered Practices**
2. **Identify common barriers to Family-Centered Care**
3. **Clarify the role of Self-Advocate & Family Advisors**
4. **Discuss key strategies to implement FCC in the developmental disability system**



FAMILY CENTERED CARE

WHAT DOES THAT ENCOMPASS?

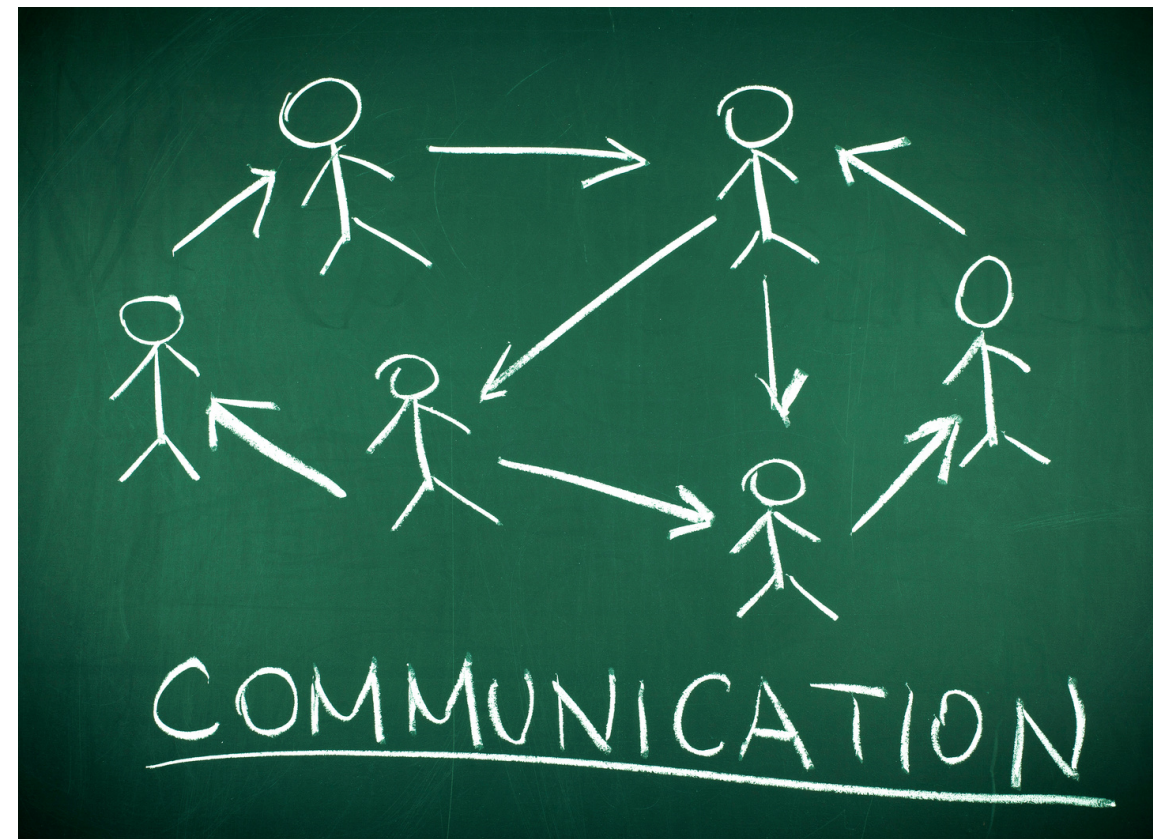
- Transparency & Open sharing of information
- Participation in planning and decision-making
- Collaboration
- Dignity and Respect

Institute for Patient & Family Centered Care, www.ipfcc.org

FAMILY CENTERED CARE

Though Family-Centered Care originated in the healthcare setting, the core tenets translate to the delivery of supports in the developmental disability arena.

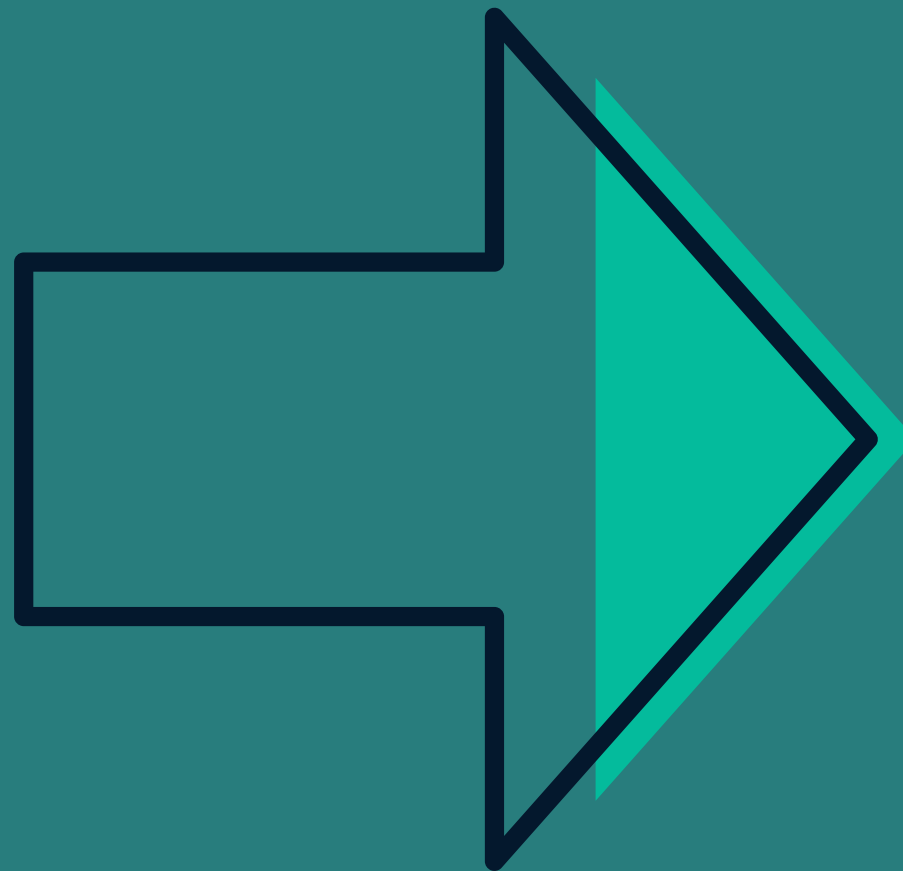
Nothing about us without us!



FAMILIES & SELF-ADVOCATES: DUAL ROLES IN FAMILY CENTERED CARE

RECIPIENTS OF SUPPORTS AND SERVICES

Families and self-Advocates utilize the DD support system to ensure independence, safety, & community inclusion, and full life as they define it



EVALUATOR/DESIGNER/ COLLABORATOR IN SERVICE PROVISION

For the highest quality of service, families and self-advocates must also participate as members of the DD system, with their input and experiences valued and utilized for system improvement

EVOLUTION OF FAMILY CENTERED CARE

**DEVELOPED IN
PEDIATRIC
HEALTHCARE SETTING**

- **Family-centered rounds**
- **Family participation in RN change of shift**
- **Family as educators to new RN's and physicians**
- **Families as mentors to other families**
- **Families as advisors in process and design**

WHY FAMILY CENTERED CARE?

FAMILY RELATIONSHIPS ARE GENERALLY THE MOST CONSISTENT, LONGEST, AND EXTENSIVE CONNECTION THAT AN INDIVIDUAL HAS

Families provide:

Context

History

Comfort

Consistency

Culture



WHAT ASSUMPTIONS DO WE MAKE ABOUT FAMILIES IN THE DD SYSTEM?

- **FAMILY IS OVER/UNDER INVOLVED**
- **FAMILY CANNOT UNDERSTAND THE COMPLEXITY OF THE SYSTEM**
- **FAMILY EXPECTATIONS ARE UNREALISTIC**
- **FAMILY GOALS ARE NOT IN LINE WITH WHAT IS POSSIBLE**
- **FAMILY SHOULD TAKE CARE OF THEIR OWN ADULT CHILDREN**
- **FAMILY CAN BE HYPERVIGILANT**



FAMILY PERCEPTIONS

What comes to mind
when I say
developmental
disability professional?



BARRIERS IDENTIFIED BY FAMILIES

"They only seem to communicate with me when there is a problem."

"No matter how many times we talk about it, the medications continue to be given at the wrong times or not at all. I can help the figure this out but they are defensive when I try to give guidance."

"No one returns my calls. I don't know what to do anymore. I leave messages, send emails, but I can't reach anyone. I think they are overwhelmed, but I need to be included in how this all rolls out."

Common theme: Lack of inclusion & Communication

BARRIERS TO FAMILY CENTERED CARE

- Historical tendency to provide "for" instead of "with"
- Lack of consideration regarding diversity, culture and equity
- Assumptions about family knowledge
- The tendency for professionals to be seen as the "experts"
- Time
- Limited resources
- Lack of experience in including families and SA's as advisors



WHAT DOES A FAMILY- CENTERED DD PROVIDER/ SYSTEM LOOK LIKE?

- Individuals and families work in partnership to define the goals and support needs, both individually and systemically
- Individual privacy is protected and respected
- Families and SA are involved in decision-making at all levels regarding their own supports and services
- Communication is consistent, open, supportive, and welcomed
- **Constructive feedback is not only welcomed, but invited and valued**
- Services and supports are easy to understand and access

**DO FAMILY EXPERIENCES
AND PERSPECTIVES
ALIGN WITH
PROVIDER/SYSTEM
EXPERIENCES &
PERSPECTIVES?**



What families tell us they need in systems:

- Change as the family's needs roles, and ages change;
 - Encourage families to express their own needs and decide how their needs will be met;
 - Treat people with disabilities and their families with dignity by respecting their individuals' choices and preferences;
 - Respect cultural, economic, social, and spiritual differences;
 - Encourage families to use the natural community resources; and
 - Provide supports and services that are easy to find and easy to use.
 - Provide families with equal access regardless of where they live
- Kathie Snow is the parent of two children, one of whom has a disability, a 1991 Graduate of the Texas Partners in Policymaking Leadership training program. She now lives in Colorado with her family and has recently been awarded a contract to be the Coordinator for Idaho partners for 1997.*

BREAK IT DOWN

SYSTEMS

- How are families and self-advocates included in DD system development & change?
- Families/SA as partners in protocol and process design
- Family knowledge and experience is highly valued and sought out

SERVICE

- Families/SA as leaders in support to other families
- Families/SA included in the development of programs and curriculum
- Families/SA as reviewers and advisors

SUPPORT

- Families & self-advocates as full participants in planning and design of individualized supports
- SA & Families as decision-makers in services and supports
- Families and SA's regularly participating in evaluation of supports

FCC CONTINUUM

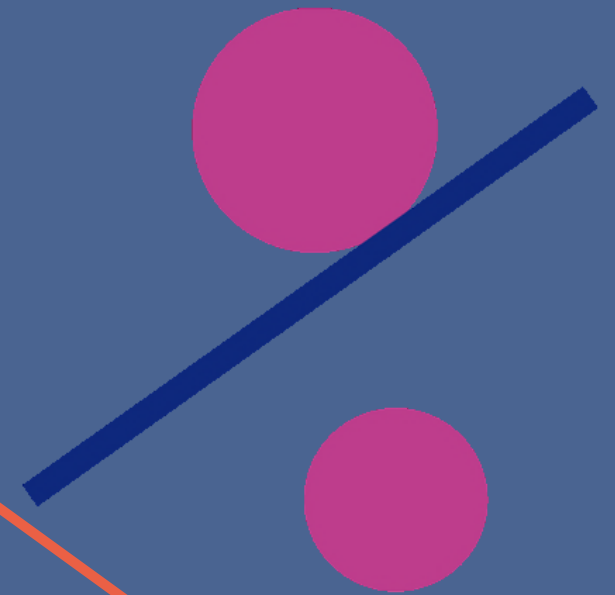
Family/SA invited to review curriculum, processes and offer feedback regularly

Family invited to participate on a Family Advisory Board/SA invited to SA Advisory Board

Family invited to share information and preferences

SA provided high quality supports

Family/SA are integral to program system functioning. They are a part of hiring and staffing, sit on the Board of Directors, and are always included in policy/process change.



WHAT ROLES CAN FAMILIES AND SELF- ADVOCATES PLAY IN QUALITY IMPROVEMENT?

- **EDUCATORS**
- **ADVISORS**
- **VOLUNTEERS**
- **MENTORS**
- **REVIEWERS**



FCC Into Action: Direct Service

Communication

Family/SA is invited by their PSW/DSP to design a system of communication that best meets their needs. The system is regularly evaluated and changed based on feedback from SA and family.

Define Family

SA & Family define (versus system defines) who their family consists of and how that group will be included in planning

FCC Into Action: Providers

Facility

Families participate in a facility walk-through to discuss functionality of environment, construction, and improvements needed

Curriculum

Families review an upcoming curriculum on soft skills in employment for potential job seekers and offer guidance on wording, accessibility, and potential teaching strategies

FCC Into Action: Systems

Family/SA Advisory Board

Select group of SA's and Family Advisors meet regularly with staff to discuss policies, process, changes, and family/SA experiences

Families/SA as Educators

Families/SA's participate in staff education, sharing experiences, barriers, examples, and guidance to support staff in gaining an understanding of family needs/experiences/perceptions

HOW TO START? EVALUATE CURRENT PRACTICES

FAMILY INVOLVEMENT

How are families, guardians and self-advocates included in the planning and design of our daily supports/programs?

FAMILY FEEDBACK

How are we inviting families to regularly share their experiences within our programs? Do we value SA/family experience?

UTILIZING FAMILY GUIDANCE

What systems are in place to integrate family guidance and experience into our daily practice and long-term planning?

WHAT DO YOU NEED IN A FAMILY OR SELF-ADVOCATE ADVISOR?

PERSPECTIVE

Can see beyond their own experiences and evaluate issues globally; understand that other's experiences and preferences will be different than their own

FOCUS

Are open to focusing on the current needs/projects of an organization or system, even if they might not align with their own change goals.

SHARING

Feel comfortable using their experiences for change and advocacy.

ALIGN WITH MISSION

Understand your goals, mission, and vision.

6 COMMON MISTAKES IN FCC IMPLEMENTATION

NOT PROVIDING STAFF EDUCATION REGARDING EXPECTATIONS & GOALS

NOT SELECTING FAMILIES/SA'S CAREFULLY BASED ON INTERESTS AND SKILL SET

NO FEEDBACK LOOP TO ENSURE FAMILY ADVISORS KNOW WHERE THEIR GUIDANCE WENT & HOW IT WAS USED

ASKING FAMILY/SA ADVISORS FOR FEEDBACK ON PROCESSES THAT CANNOT CHANGE

ASKING FAMILY/SA ADVISORS TOO LATE IN A PROCESS TO MAKE NEEDED SHIFTS

NOT BEING CLEAR WITH ADVISORS ABOUT EXPECTATIONS AND ROLE

WHERE TO START?

**EVALUATE
CURRENT
CULTURE**

**SURVEY
FAMILIES**

**BUILD
ADVISORY
BOARD**

**IDENTIFY
CONCRETE
PROJECT**



RESOURCES & TOOLS

Institute for Patient and Family-Centered Care

www.ipfcc.org

American Association on Intellectual and Developmental Disabilities

www.aaid.org

lifecoursetools.com

spanadvocacy.org

familyvoices.org/lfpp/

<https://familyvoices.org/wp->

[content/uploads/2018/10/FamilyVoices_LPFCH_assessing_family_engagement_April2018.](https://familyvoices.org/wp-content/uploads/2018/10/FamilyVoices_LPFCH_assessing_family_engagement_April2018.pdf)

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https://www.aucd.org/docs/publications/2019_family_fabric.pdf

THANK YOU!

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