

Leadership With Purpose

From Try to Triumph

Partnering through Transition



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Today's Objectives:

As a result of this session, participants will more deeply understand a parent's perspective of:

1. The progression of family leadership and key indicators for successful partnerships.
2. How a successful transition is the ultimate indicator of an effective medical home.
3. Throughout the Lifecourse, how the community is a key strategy for successful transition

Further introduction...

- *Parent of a young adult with complex health needs*
- *Background in marketing and media*
- *Former corporate trainer*
- *Former Director of Colorado's Medical Home Initiative*
- *National expert on healthcare transition, triple aim principles, patient/family centered care*

Life as a Single Mom



Perseverance



An Invitation to the White House!



Moving Forward!





Reality of Systems Navigation



Laughter is part of the strategy



It's a Family Thing....



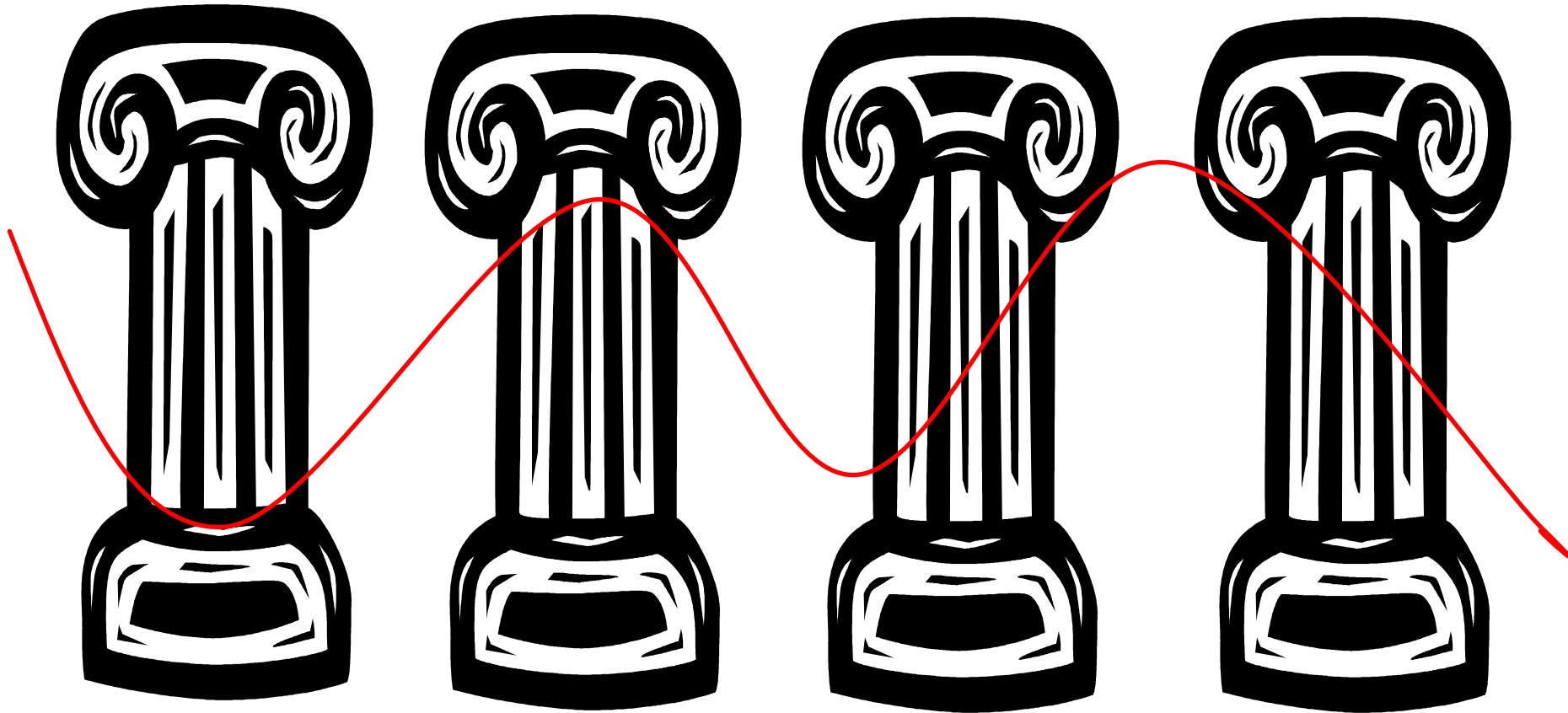
Families are a horizontal thread in a vertical system.

Health

Housing

Education

Human Services



The Short Bus



The Bus Buddy Program



Holly's Bus Buddy Program



Fox Creek Elementary

Learning... every child, every day
6585 Collegiate Dr.
Highlands Ranch, CO 80126
303-471-3735

Diane R. Smith
Principal

Bob Winter
Assistant Principal

May 14, 2001

Dear Parents and Students:

We're thrilled to celebrate with you an exciting announcement about one of your fellow classmates. Holly Fiscus will be joining you all as a regular rider on your bus. This is exciting because Holly is a 5th grader with special needs who is now ready to ride the bus with her peers.

Holly is developmentally delayed and has been dealing with the challenge of seizures on a daily basis. However, for over six months, Holly has not experienced any seizures! This break-through is awesome, as Holly can now begin to enjoy many of the childhood experiences most of us take for granted...like getting to ride the "Big" bus with her classmates and friends.

For those of you who have met Holly, you know she is a very social person. Although she cannot speak, Holly loves to interact with her peers whenever possible. She typically communicates her needs with gestures, pointing or hand-on-hand guidance. Her joyous laughter and smiles are contagious!

As we continue to plan for this advancement, we're inviting Holly's classmates to sign up for **Holly's Bus Buddies Program**. As Holly's **Bus Buddy**, you will be asked to sit with Holly during the bus ride, (she will be buckled in), and help get her backpack off the bus. (Holly loves riding the bus, and has no behavioral challenges during transport.) Holly's aid will meet the bus at school, and a member of Holly's family will be at her bus stop at the end of the day to complete Holly's journey. If you are interested in signing up for a one-week commitment, please complete the information below and return it to Mrs. Smith.

We are excited to share Holly's accomplishments with her peers, neighbors and the entire community! Feel free to call her parents at home at 303-345-5909 to discuss any questions you may have. This is an exciting time! Thank you for your support and kind consideration.

Sincerely,

Scott and Eileen Forlenza - Holly's Mom and Dad
Diane Smith - Principal, Fox Creek



HOLLY

Yes, I am interested in being a **Bus Buddy** for Holly.

I'm considering signing up as a **Bus Buddy**, but I need more information. Please contact me at _____ Student's name _____

Parent's name(s) Dawn Wood Phone# 303-791-0274

Student's Teacher/Grade/Track Jessy Wood / Howell / c

Embrace the Possibilities

Sometimes the system places us in a fear-based state of mind.

Vs.

The young people were able to view the world through the lens of possibility.

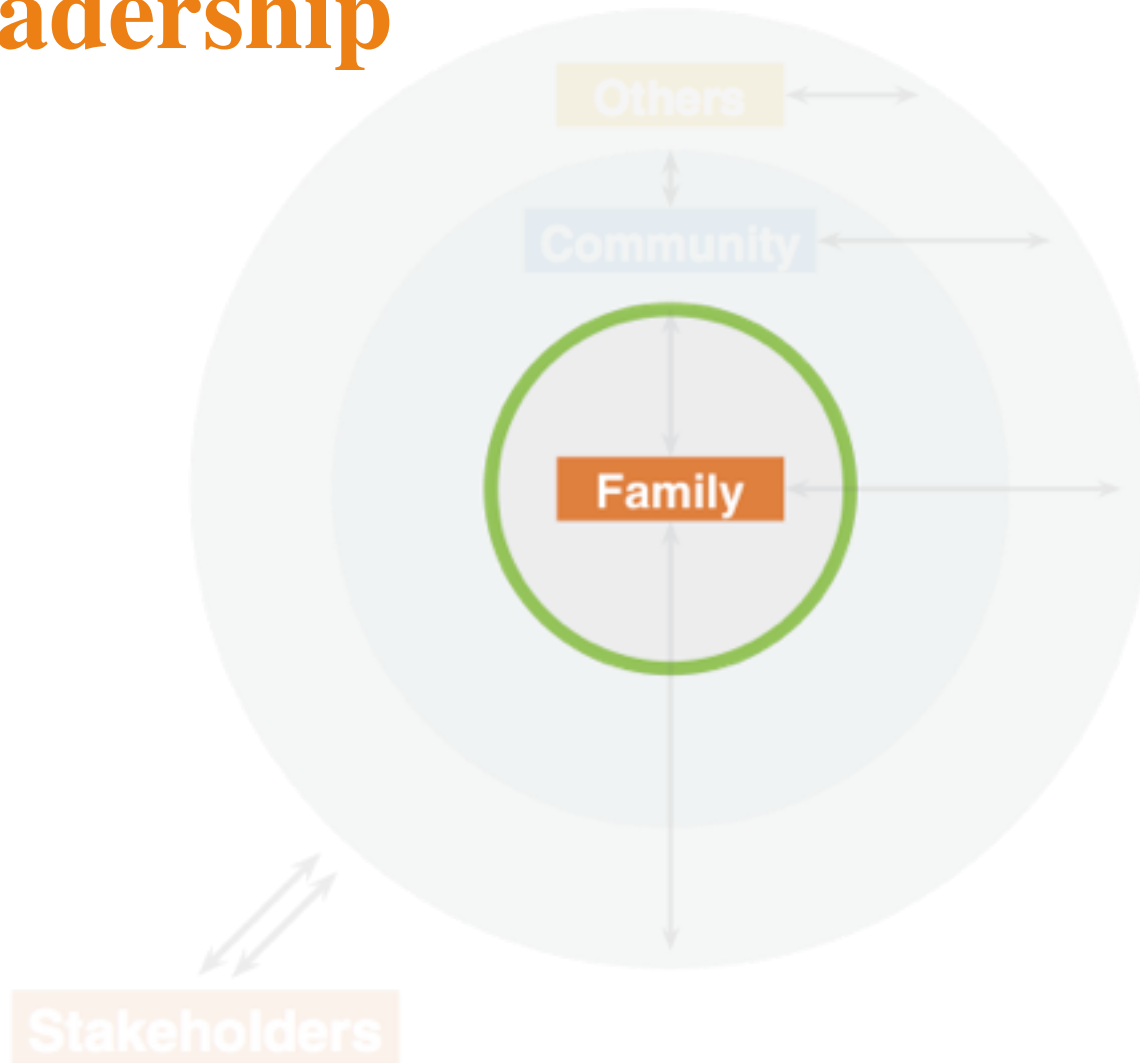
Peer support is foundational for successful transition.

- Successful transition is strongly tied to meaningful peer relationships.
- Transition is a ***process***, not an event.

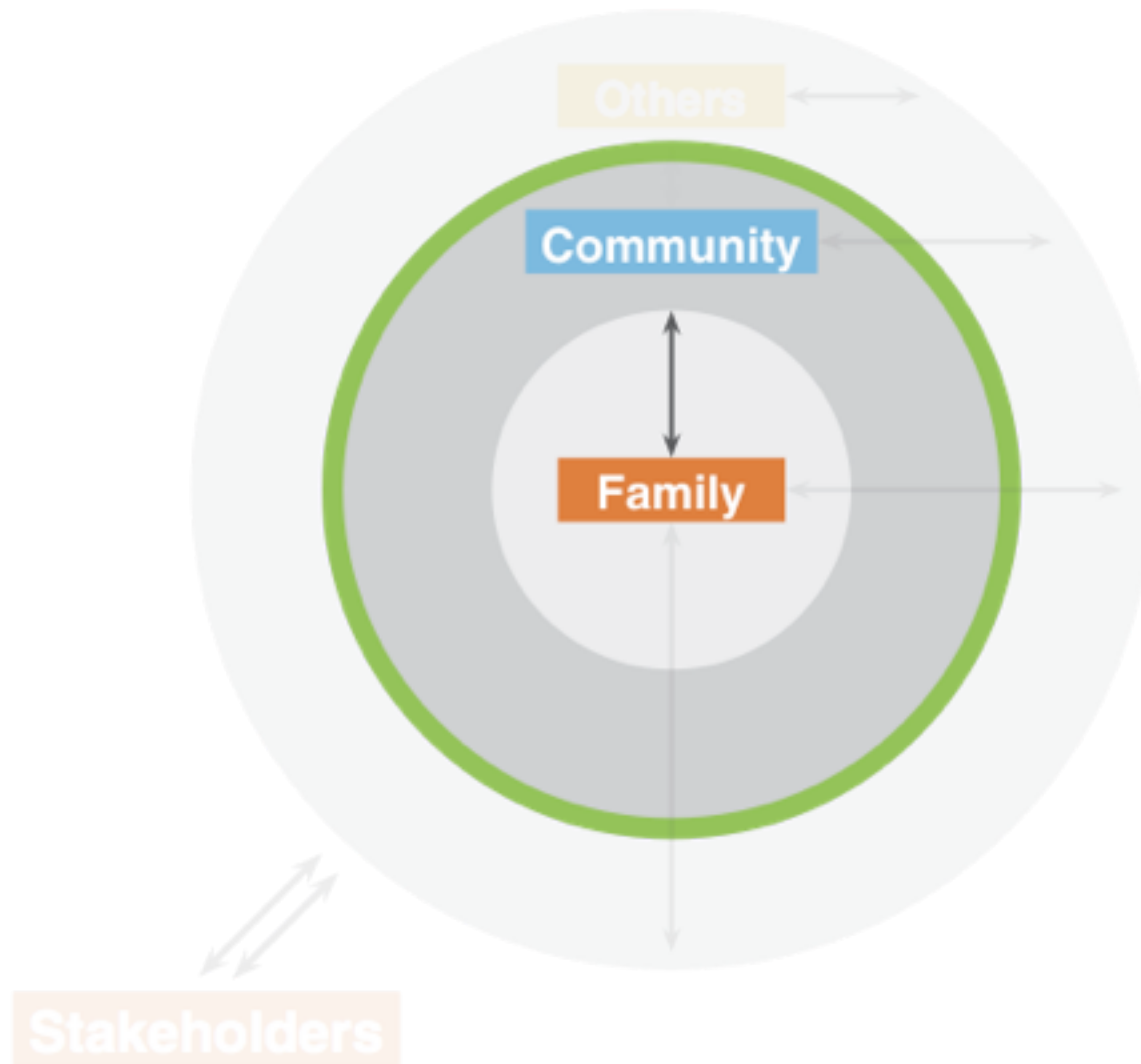
Progression of Family Leadership



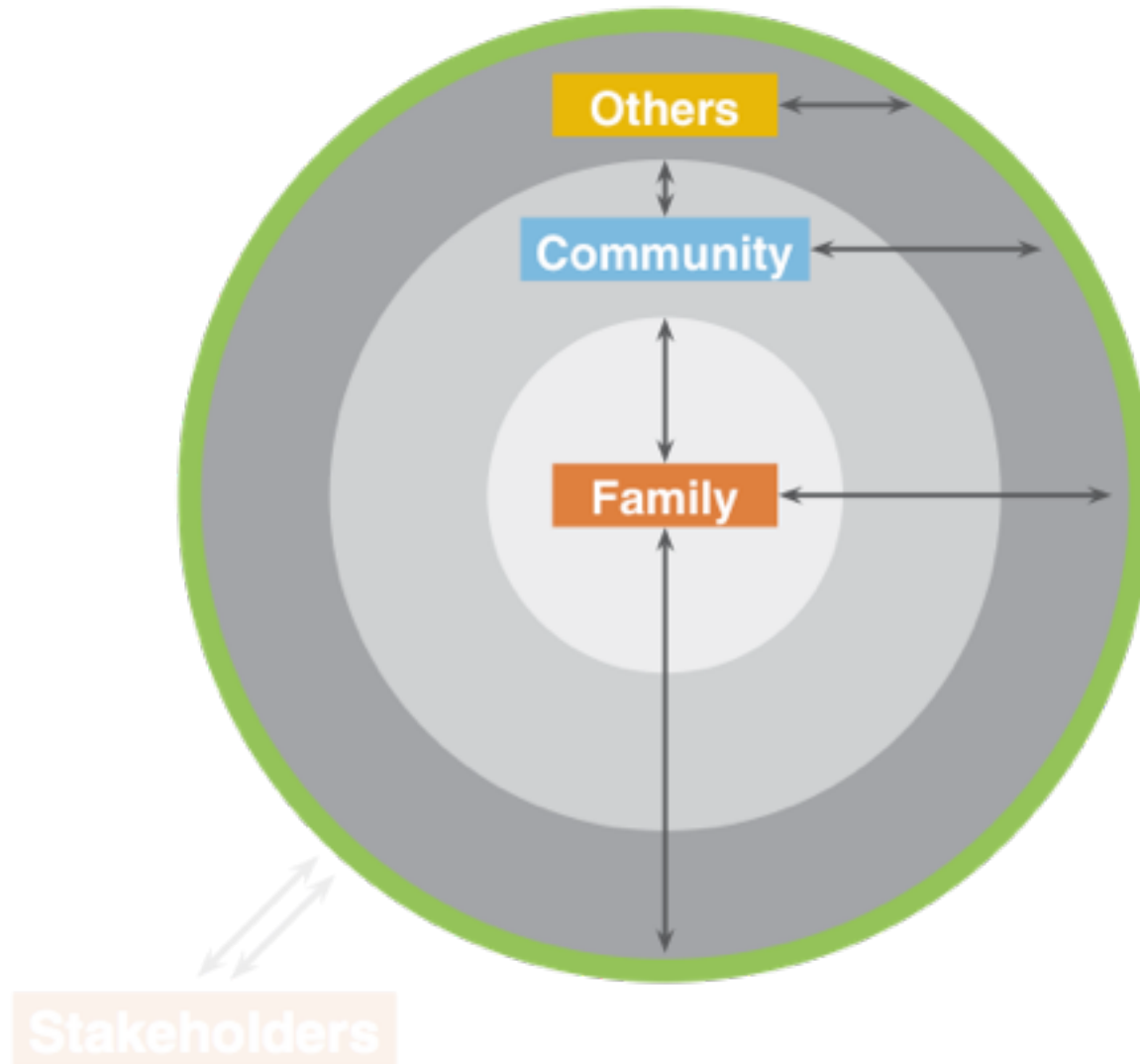
Progression of Family Leadership



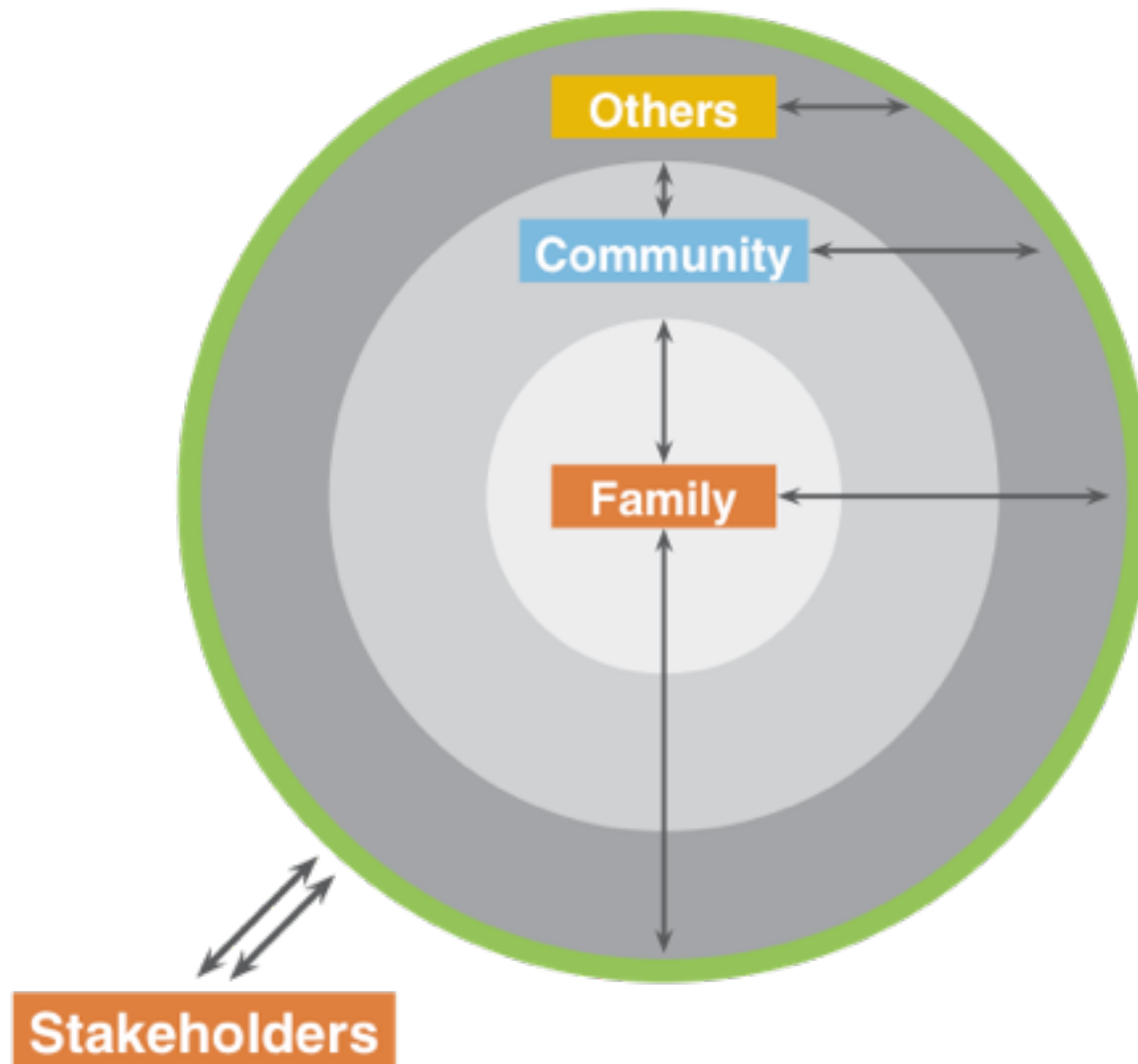
Progression of Family Leadership



Progression of Family Leadership



Progression of Family Leadership



Value at All Levels

There is value in capturing and nurturing all levels of leadership.



Diversity Matters

Expanding the roster of youth and family leaders assures a diverse perspective



The Right Partner at the Right Time

Your role is to clearly define what your needs and expectations are.

Achieving outcomes is based on our ability to understand, respect and embrace a family's experience and braid that into quality improvement.

Readiness Factors for Family Professional Partnerships

Providers

- Explore past history
- Are you ready for full transparency
- Leadership support in all directions
- Willingness to be flexible
- **Your budget is your policy statement!**

Readiness Factors for Family Professional Partnerships

Families:

- Clarify your role, expectations and accountability
- Be honest about your skills, knowledge and abilities
- Present yourself as a project consultant
- Can you represent the constituency of families
- Model partnership at all levels
- **Braid experience with knowledge**



CHRYSLER



QVC



Mythbusting

Fear-Based Thinking	Innovative Thinking
<i>Families are complainers</i>	<i>Families bring informed solutions</i>
<i>Don't understand the business of healthcare</i>	<i>They are business owners too.</i>
<i>HIPPA regs won't allow for this</i>	<i>Trained Family Leaders sign confidentiality statements like any other consultant</i>
<i>FCC takes too much time</i>	<i>Efficiency is increased</i>
<i>Families are not available to participate</i>	<i>Develop contracts for equitable pay</i>
<i>The families we work with don't care</i>	<i>We haven't tried hard enough</i>

An intentional shift from a dependency model to a partnership model.



Shift from *servicing* families to *partnering*
with families.



You don't know until you try!



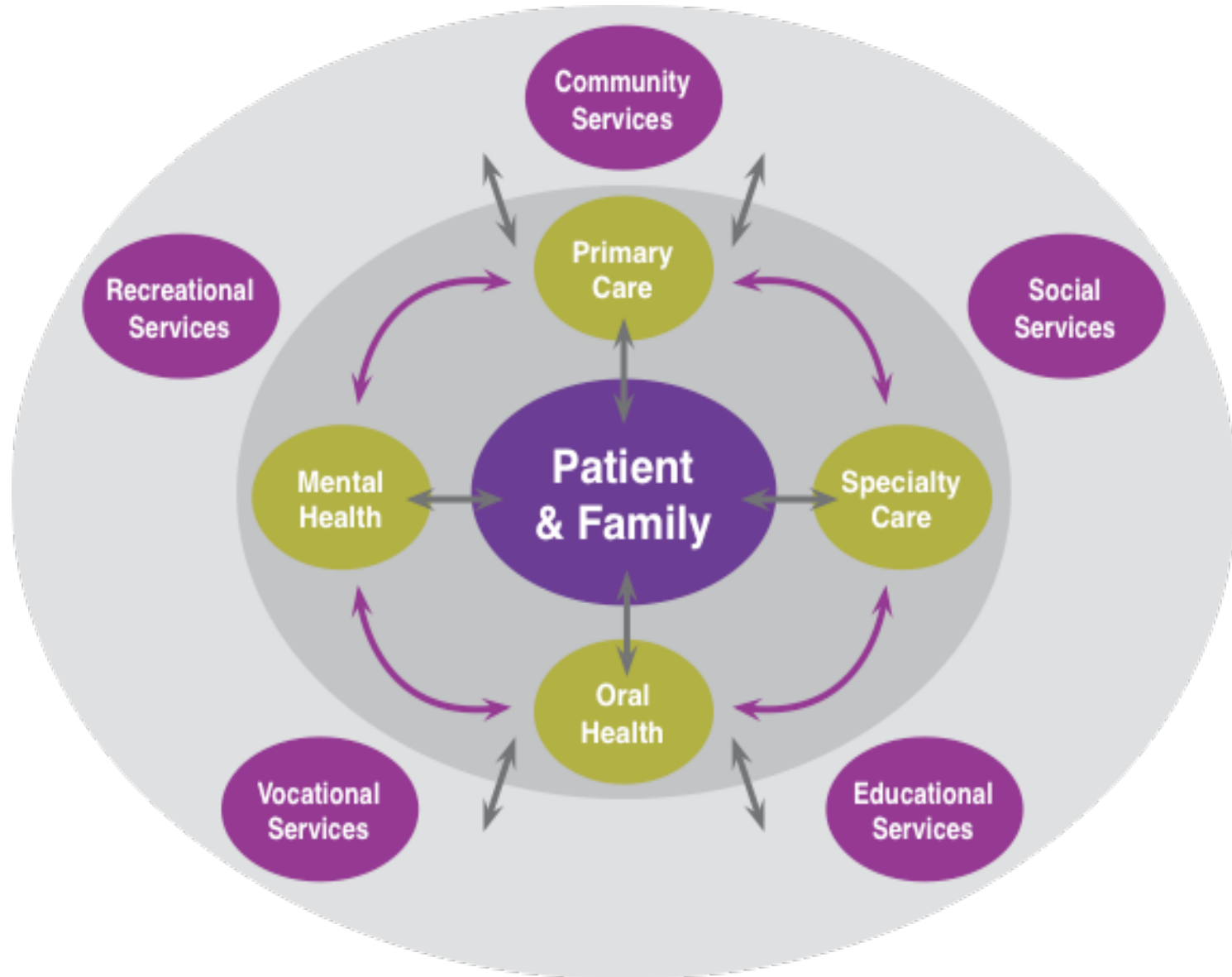
Self Assessment – Where are you?

- Partnerships from the Kitchen table to the Policy Table
- What happens at the clinical level informs what should happen at the policy level.



Medical Home Approach

Family-centered, Team-oriented Care



The Triple Aim



Source: MIT Triple Aim

The #1 Area of Quality Improvement:
Communication!

You need what?!



The Role of the Community

We forgot to tell the community!



It's a New Day

The college graduates of the class of 2010, are the first class in the history of our country to go through their entire public education alongside their peers with disabilities!

Generational Trends - Verify

- Want information – quickly!
- Value relationships
- Inter-dependent
- Digital based communication

So What... Now What?



The Next Generation of Leaders!



Can you grasp the significance?



24 Years Old and Still Trying....

- Left pediatric practice at age 19
- Went to a new system – Kaiser
- Completed the “Time to Transition Workbook”
- Requested ample time at clinic visit
- **Sent back to peds**



We've come a long way!



What Families have reported:

1. Transition policy
2. Check list for young adults
3. Check list for families
4. Asset vs. Deficit Based
5. Knowledge of Systems

Six Core Elements – GotTransition.org

1. Transition policy
2. Tracking and Monitoring
3. Readiness Tools
4. Planning with Family
5. Transfer of Care
6. Transfer Completion

Creating a meaningful life for Holly requires teamwork, communication and community.



Holly's Awakening - Communicating!

- Literacy skills uncovered at age 22
- *Facilitated Communication* methodology
- Typing has been a slow process
- **“I want a platform to teach about love.”**



Transitioning to Adult Life-Working!

- *“Just Because I Can’t Talk, Doesn’t Mean I Don’t Have Anything to Say.”*
- Featuring her words
- Tuesdays with Holly



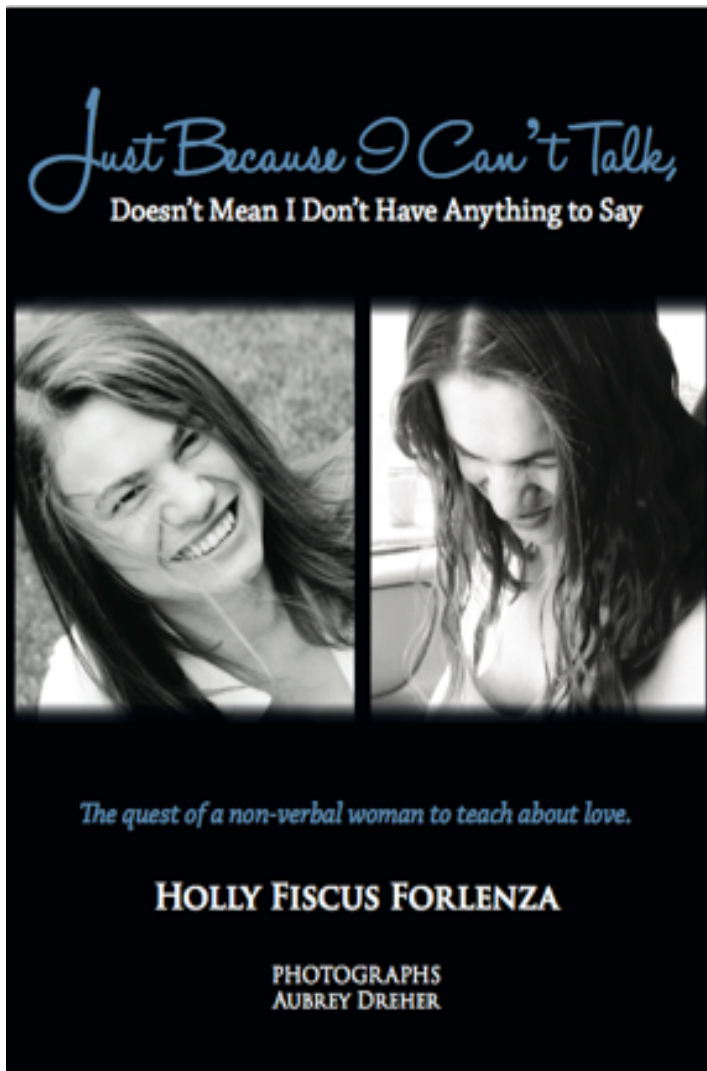
Transitioning to Adult Life

- “*God Will Sing you Home*”
- Lyrics by Holly
- Power of Community – Megan Burt

www.HollySpeaksUp.com



Infinite Possibilities!



Transition Planning – My Lessons

- *Always open to yes!*
- Isolation will rot one's spirit
- All behaviors are a form of communication
- It takes courage to be a leader

If suddenly you were awakened....

What would *you* say?

Thank You!

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