

*Leadership With Purpose*

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# Accelerating Partnerships

*Patients & Families as QI Strategists*



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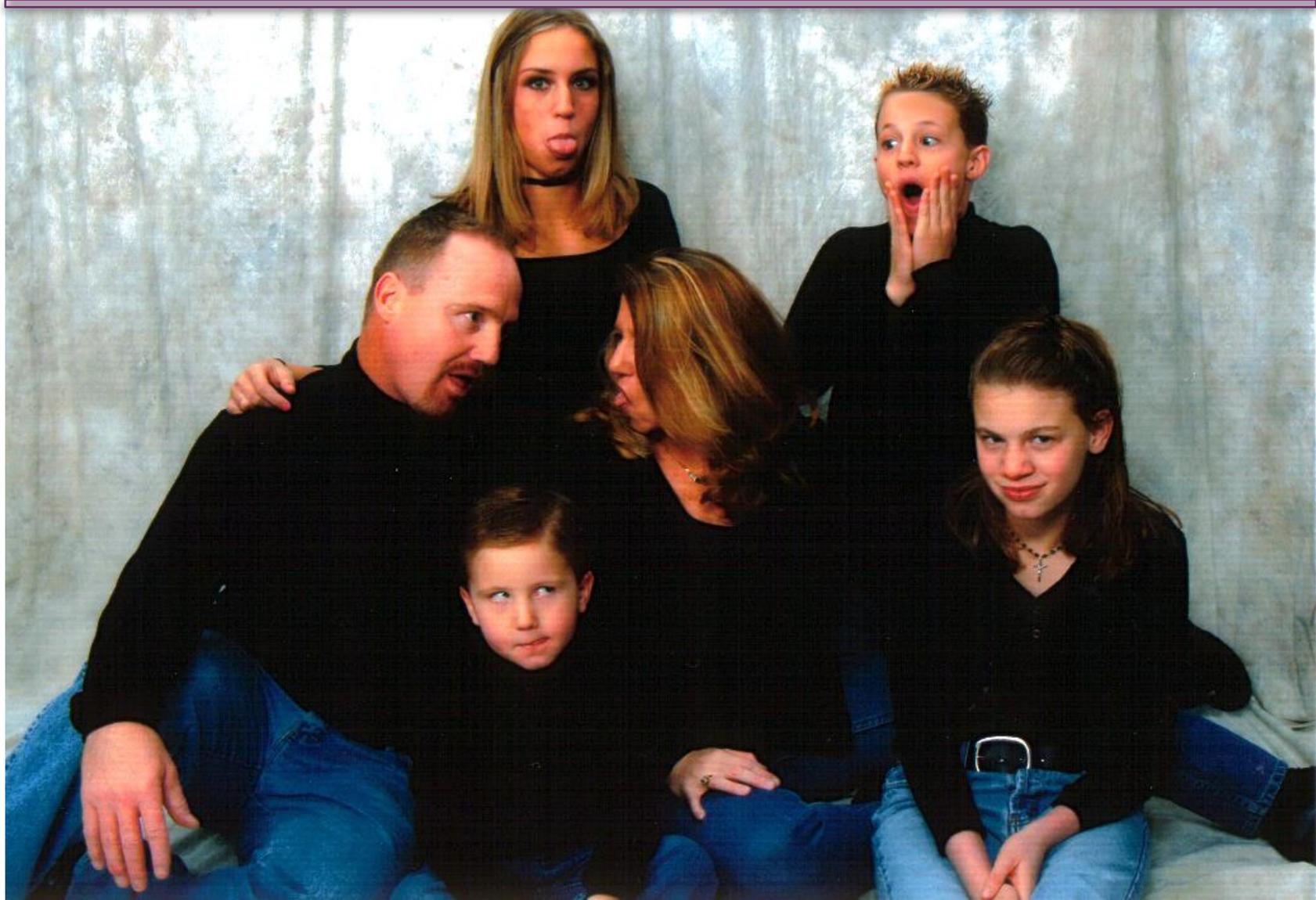
# Further introduction...

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- ***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***



# Staying open to Yes!



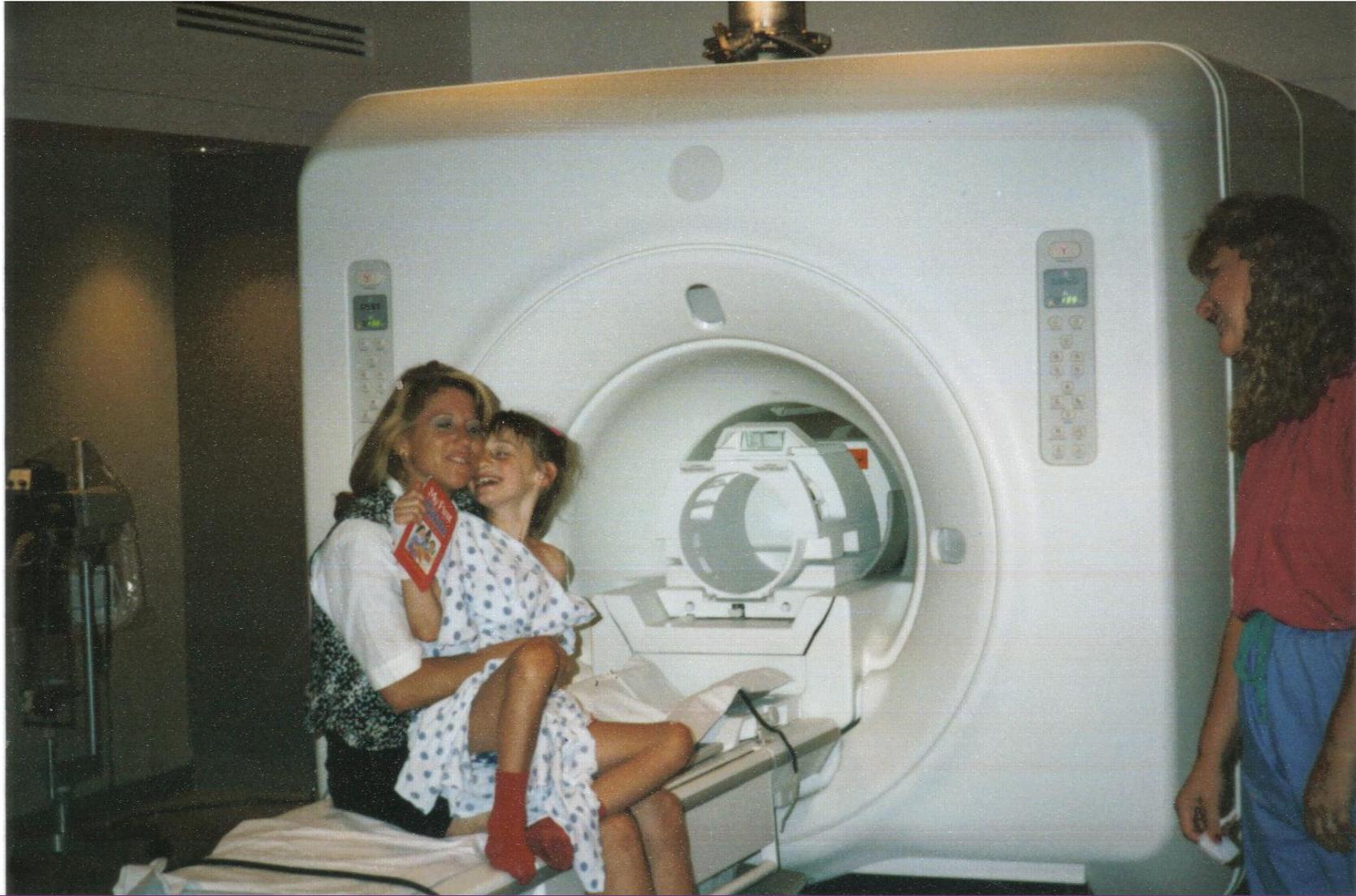
# 150 Seizures a Day



# Protection became isolation



# Searching for answers...



**On any ordinary day...**

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**CHRYSLER**

**QVC**



# The Triple Aim



Source: MIT Triple Aim

# Patient & Family Centered Care

The AAP Policy Statement on Patient and Family Centered Care – February 2012

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***“Patient and family centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient’s life.”***

# Value of Family Engagement

**“In a growing number of instances where truly stunning levels of improvement have been achieved....Leaders of these organizations often cite that putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems – as being the single most powerful transformational change in history.”**

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*Reinertsen, J.L., Bisagnano, M & Pugh, M. Seven Leadership Leverage Points for Organizational Level Improvement in Health Care. 2<sup>nd</sup> Edition, IHI InnovationSeries, 2008.*

# Value of Family Engagement

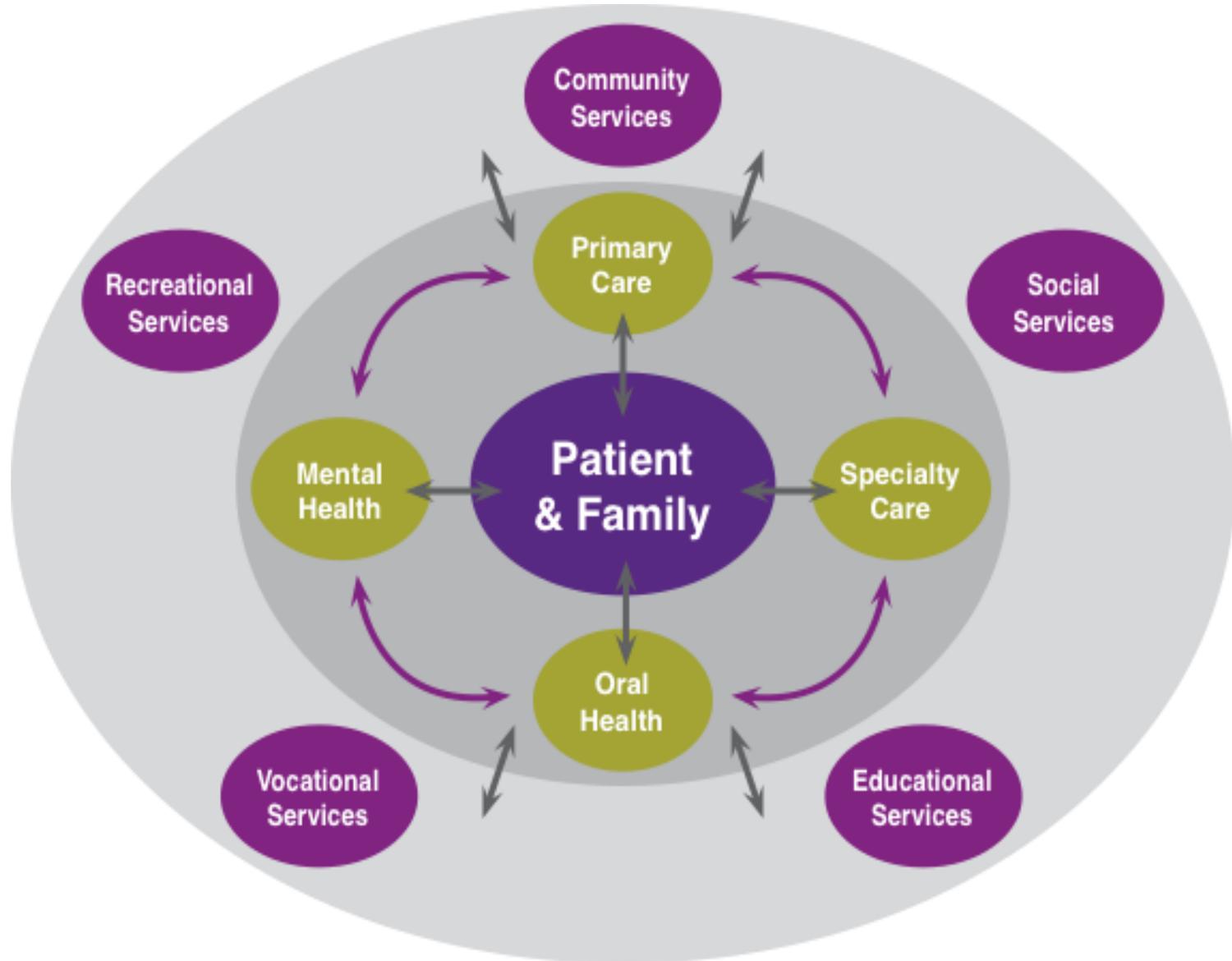
**“We envision patients as essential and respected partners in their own care and in the design and execution of all aspects of healthcare.”**



Leape, L., Berwick, D., Clancy, C., & Conway, J., et al. (2009). Transforming healthcare: A Safety Imperative, BMJ's Quality and Safety in Health Care.

# Medical Home Approach

*Family-centered, Team-oriented Care*



# Beyond the Exam Room

- Partnerships from the Exam Room to the Board Room.
- What happens at the clinical level informs what should happen at the policy level.



# The #1 Area of Quality

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## Improvement:

# Communication!

# Health Systems need a Communication Mechanism

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**Families have valuable information to share...**  
**how are you harvesting their insight?**



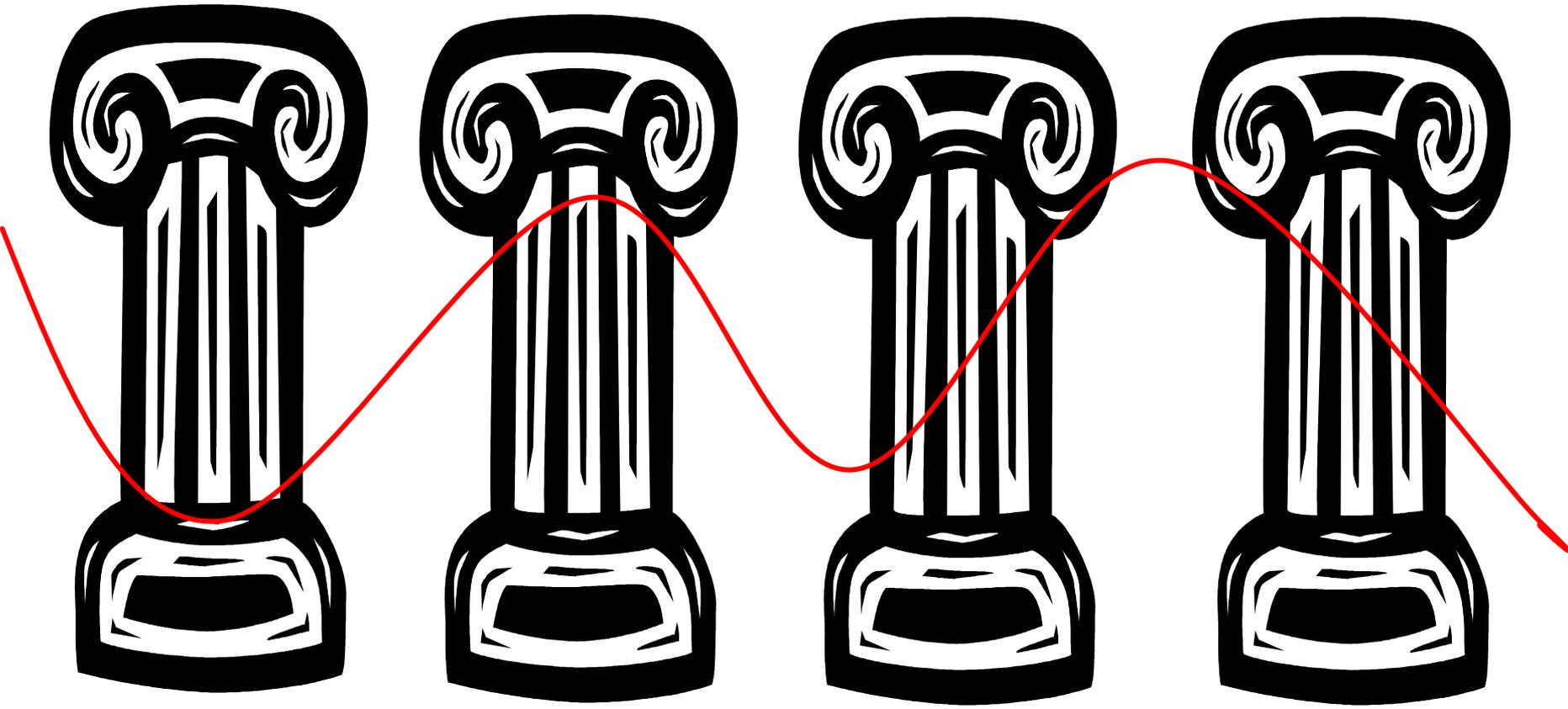
# Families are a horizontal thread in a vertical system.

Health

Healthcare

Insurance

Care  
Coordination



# The Short Bus

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# 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 303-346-5909 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 Jordyn Wood / Howell / c

# **Embrace the Possibilities**

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***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.

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

# So What... Now What?





# Myth Busting

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

**We forgot to tell the community!**



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



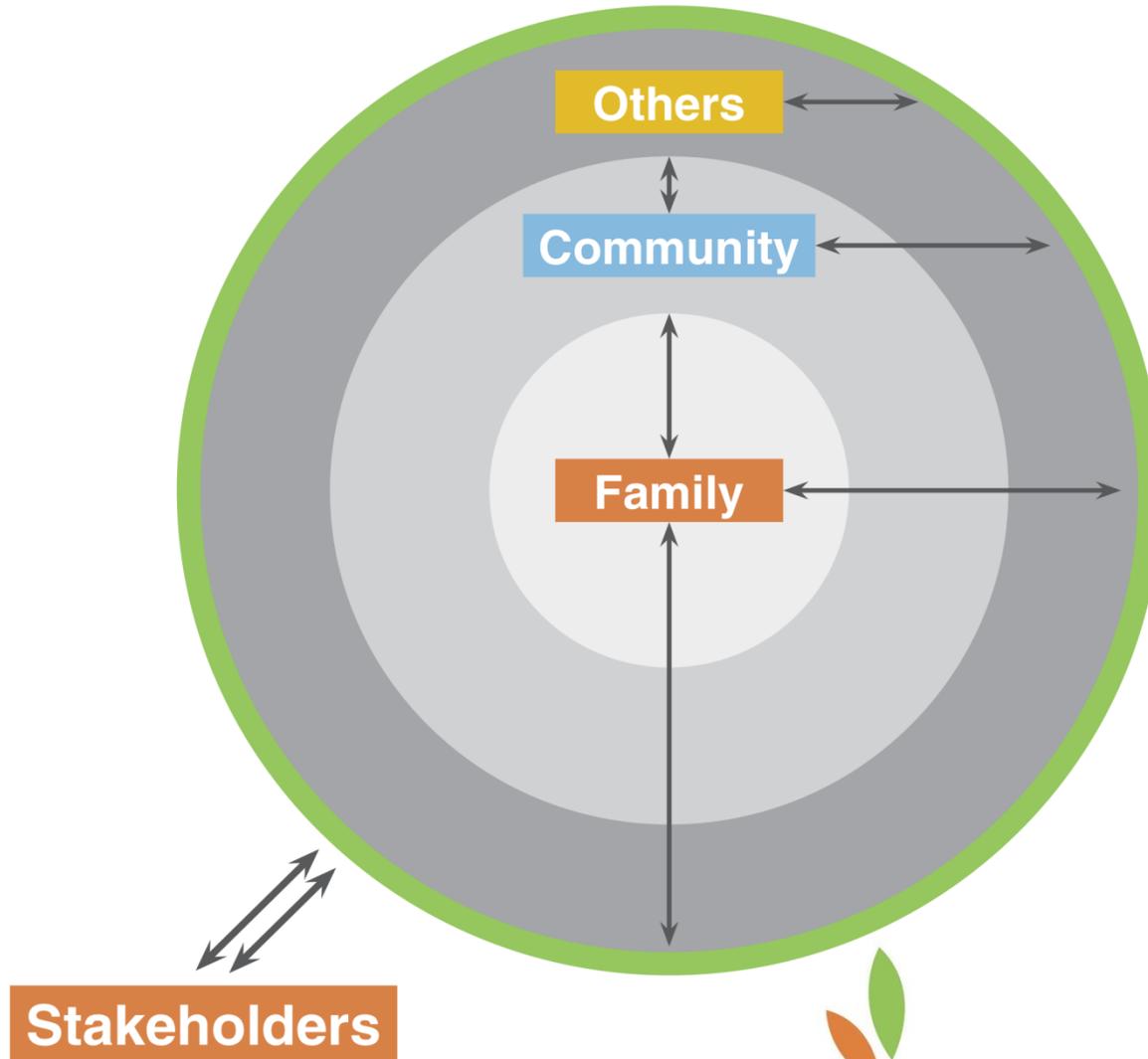
# An intentional shift from a dependency model to a partnership model.



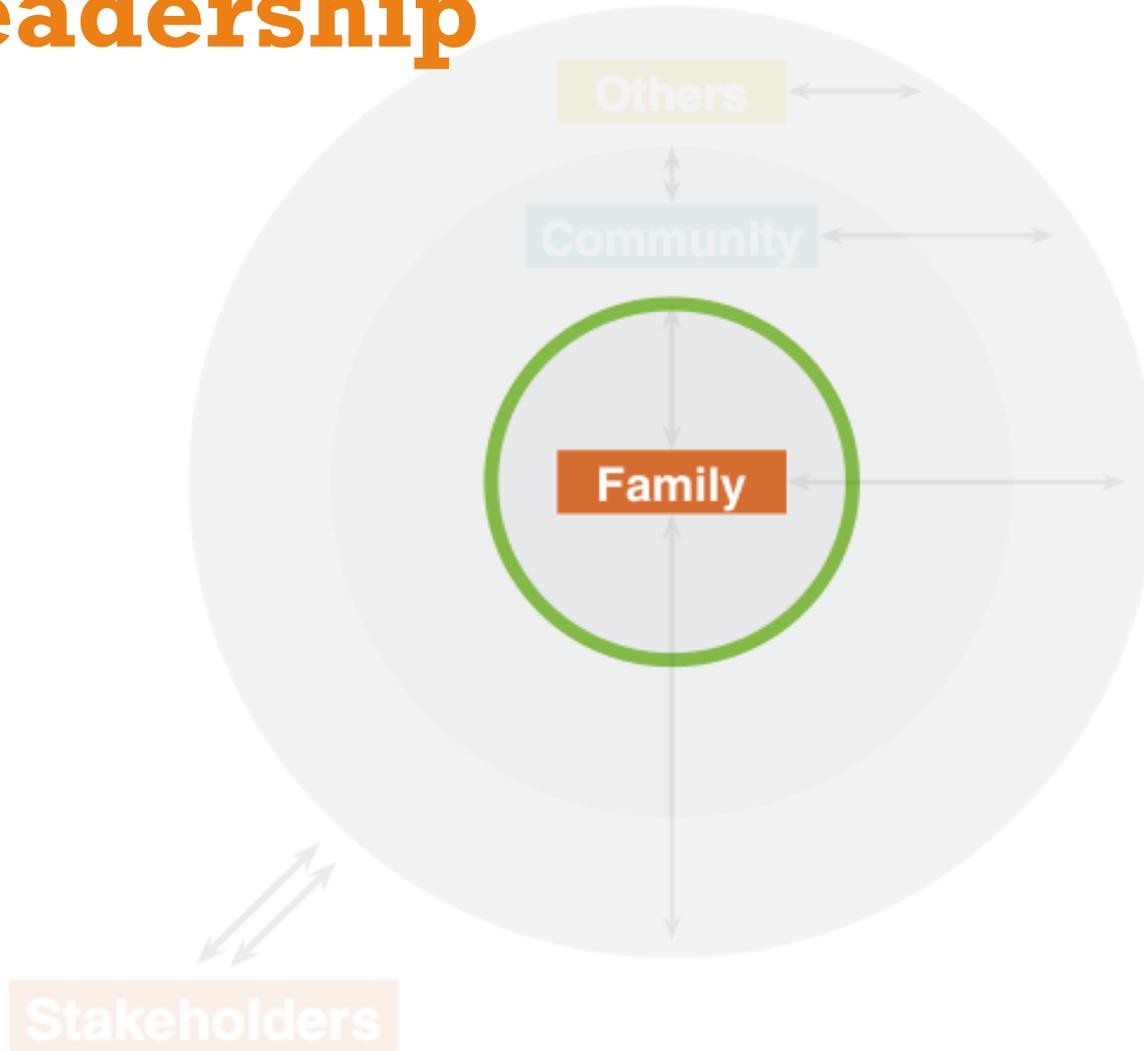
**You don't know until you try!**



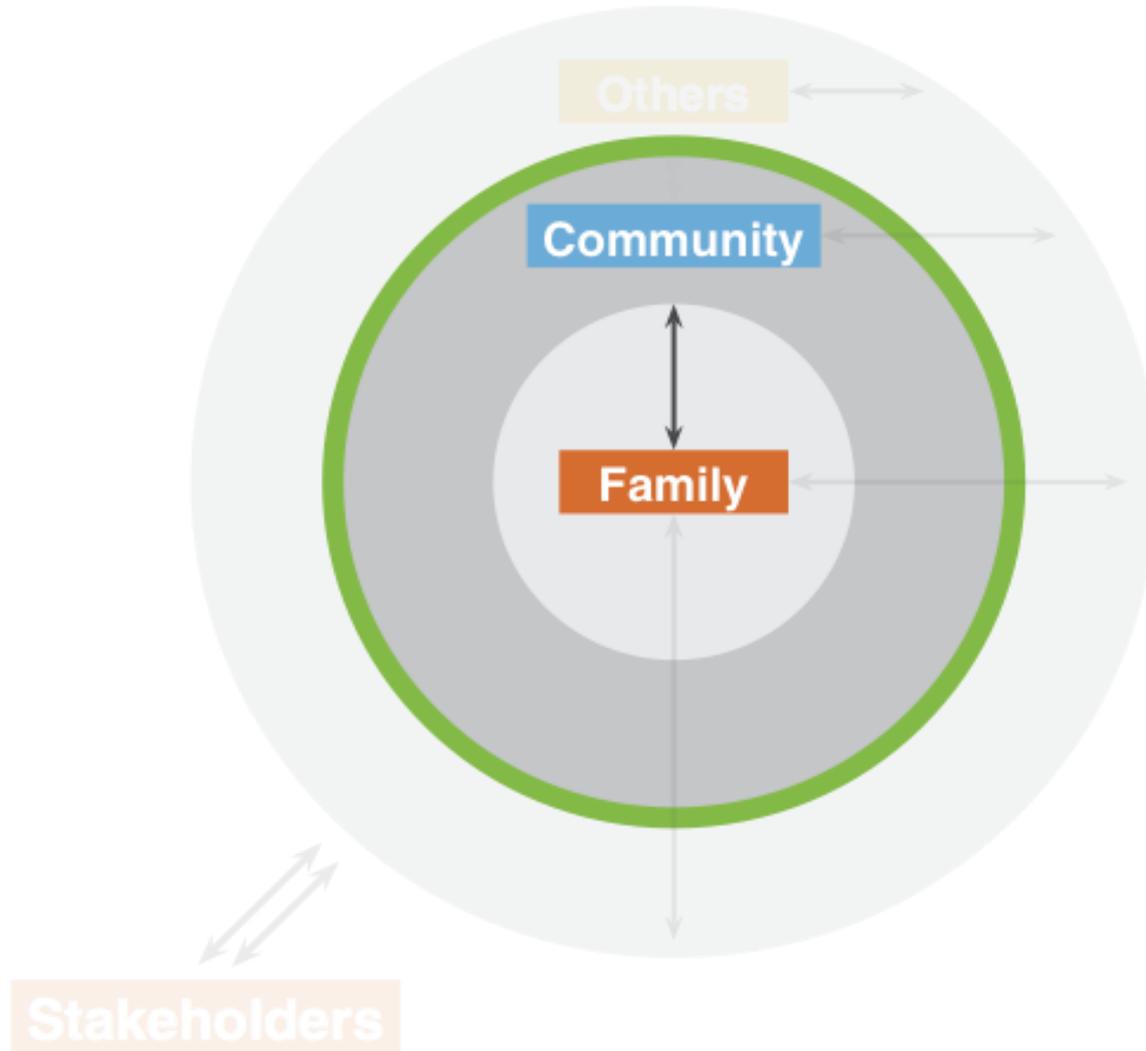
# Progression of Family Leadership



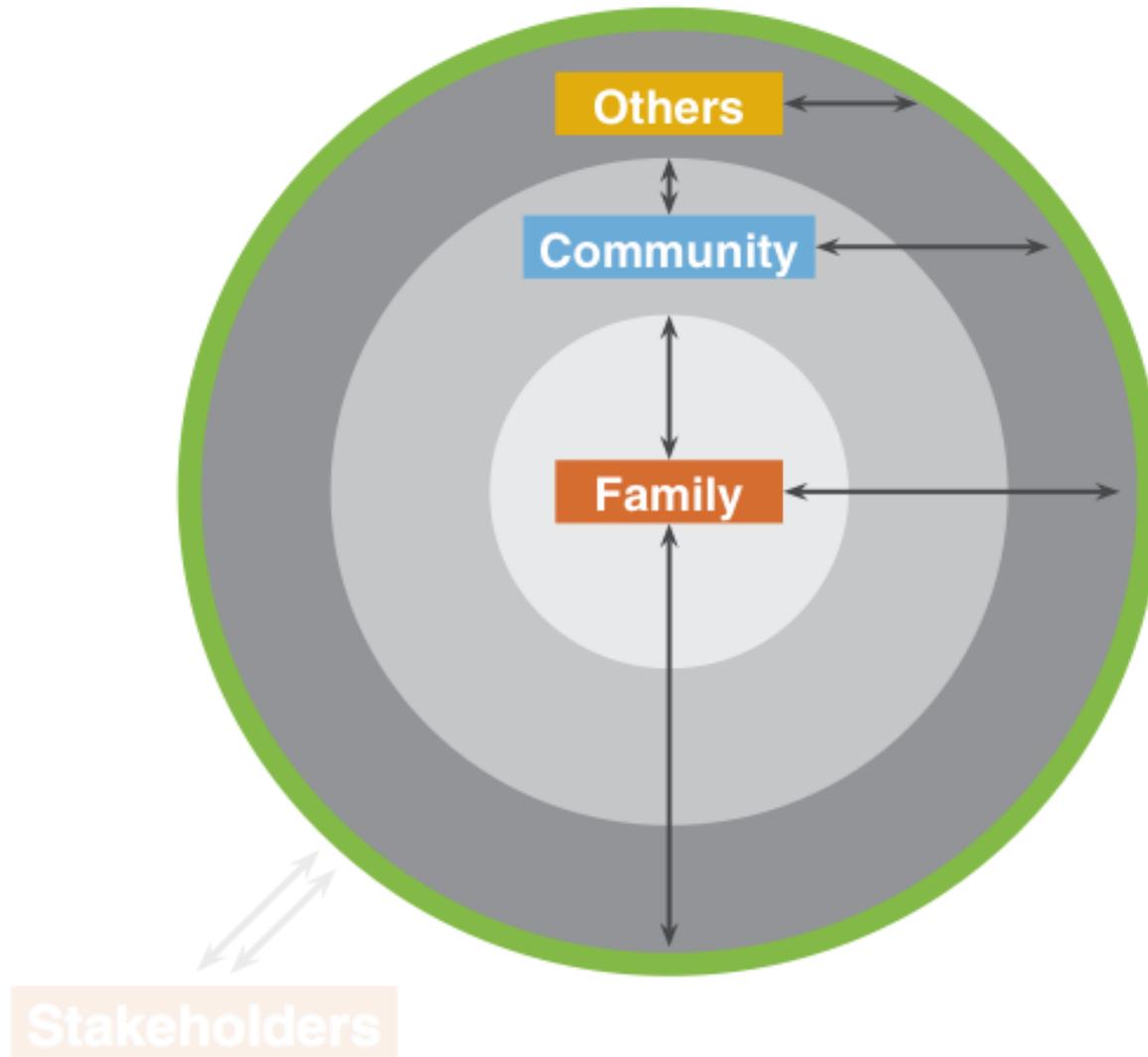
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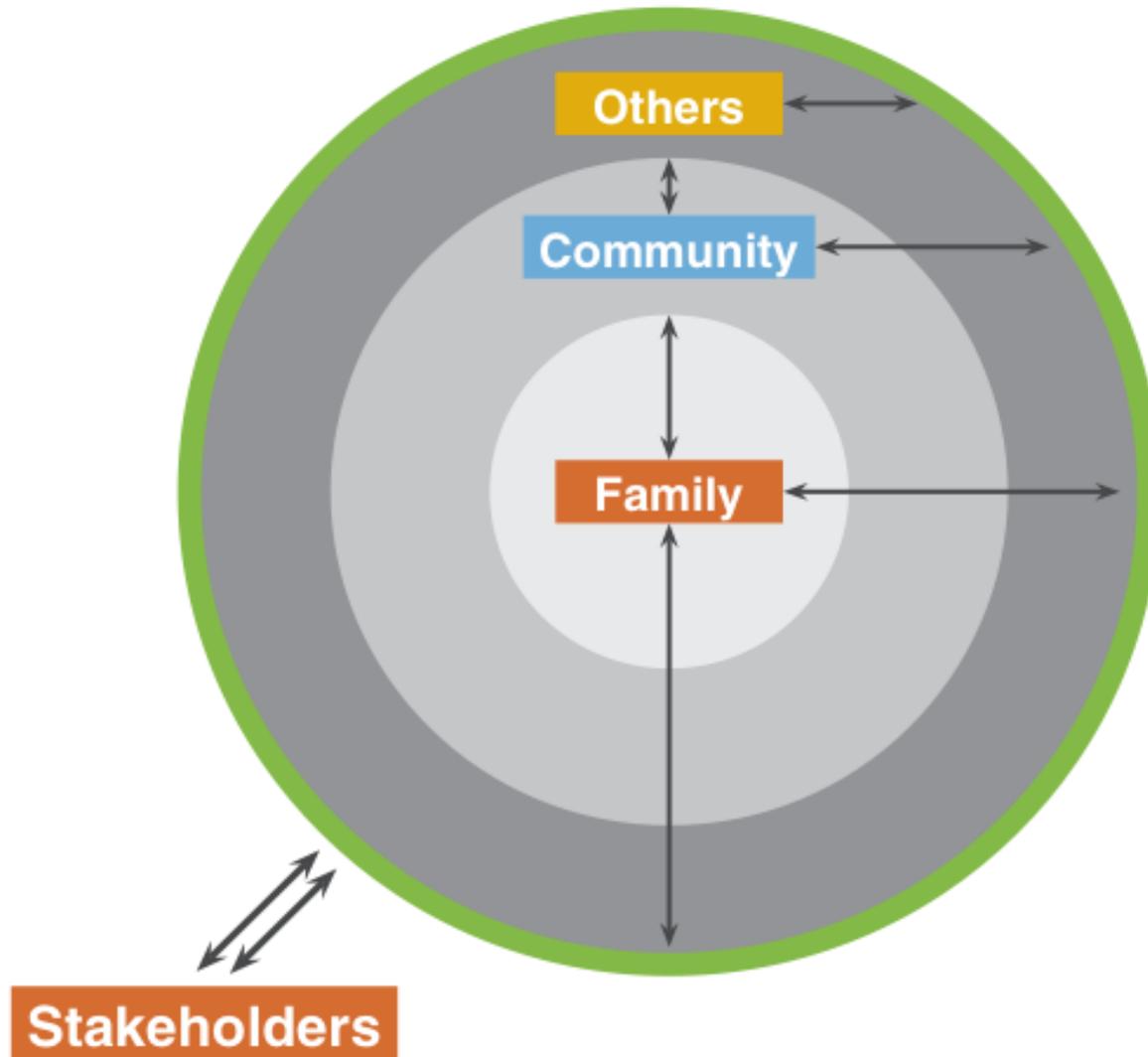
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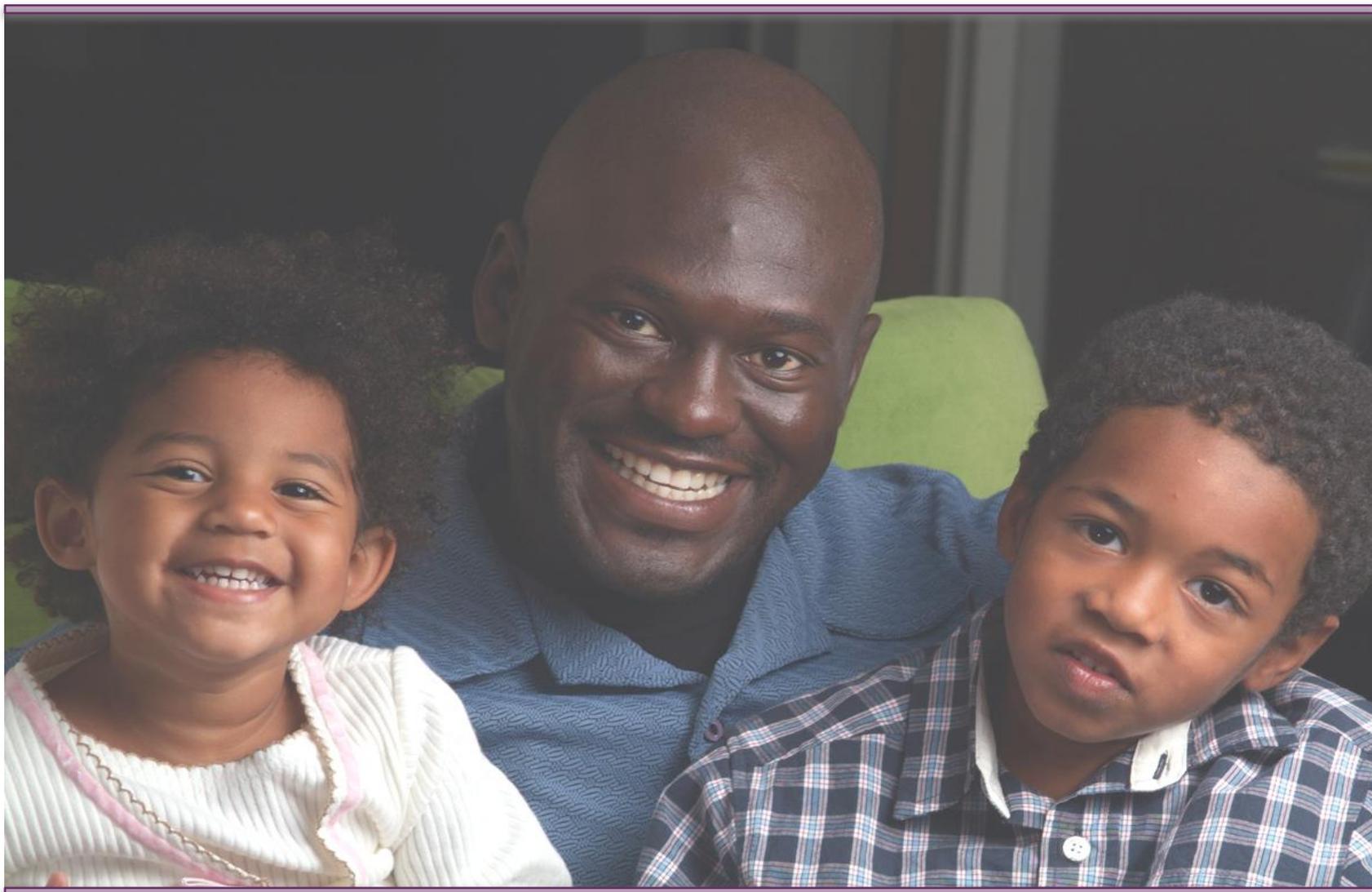


# Progression of Family Leadership



# Value at All Levels

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# Diversity Matters

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



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# Readiness Factors for Health Systems

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

# Strategies to embed patients/families in quality improvement initiatives.

- **Patient Family Advisory Council – consider: Evaluation data, strategic plan, staff**
- **Always co-present with a patient/family**
- **Consistent trainings AND evaluations**
- **Engage young adults**

# **A New Workforce**

***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!***

# The Next Generation of Leaders!



**Can you grasp the significance?**

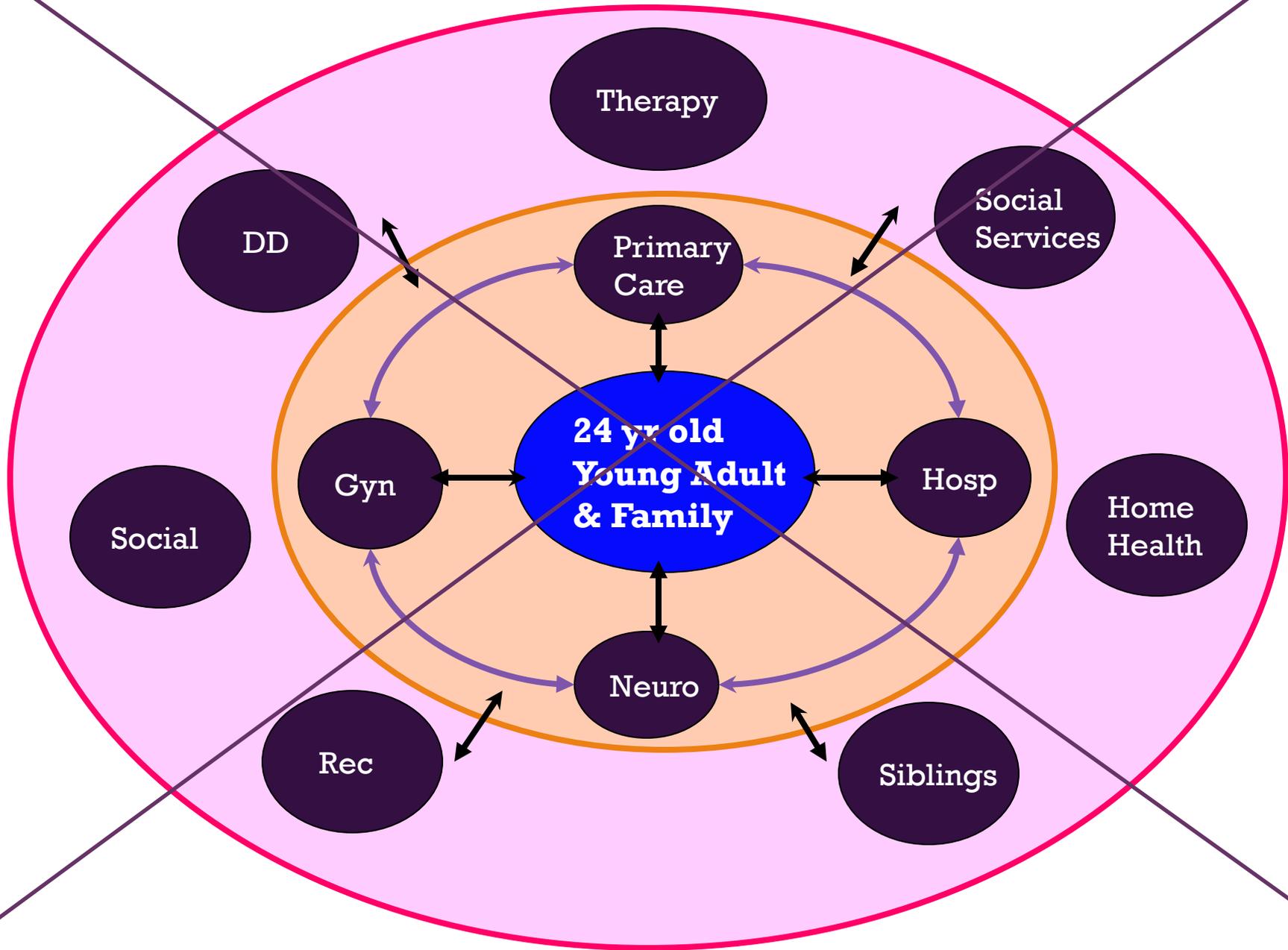


# 24 Years Old and Still Trying....

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



# Canceled Due to Hospital Policy



**We've come a long way!**



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



# Supported Communication -

- **“I think your daughter has literacy skills.”**
- **Intensive therapy**
- **Transformative**
- **Perseverance**



# Transitioning to Adult Life

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

[www.HollySpeaksUp.com](http://www.HollySpeaksUp.com)



# Transitioning to Adult Life-Working!

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

[www.HollySpeaksUp.com](http://www.HollySpeaksUp.com)



# Infinite Possibilities!

*Just Because I Can't Talk,*  
Doesn't Mean I Don't Have Anything to Say



*The quest of a non-verbal woman to teach about love.*

**HOLLY FISCUS FORLENZA**

PHOTOGRAPHS  
AUBREY DREHER

# *“Just Because I Can’t Talk, Doesn’t Mean I Don’t Have Anything to Say”*



I have been  
called retarded  
from the day  
I was born.  
It makes me  
feel worthless.  
I hate that word.

***“I have been  
called retarded  
from the day I  
was born. It  
makes me feel  
worthless.  
I hate that word.”***

[www.HollySpeaksUp.com](http://www.HollySpeaksUp.com)

# Holly speaks out.



***Please help people to understand other people are impacted by their words.***

***Your kindness matters.***

**We've got a song to sing!**





# Thank You!

## Resources

[www.HollySpeaksUp.com](http://www.HollySpeaksUp.com)

[www.EileenForlenza.com](http://www.EileenForlenza.com)

[www.ipfcc.org](http://www.ipfcc.org)

[www.gottransition.org](http://www.gottransition.org)

[www.http://odpc.ucsf.edu](http://www.http://odpc.ucsf.edu)



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