

# CATCHing Family Engagement

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Change Agents



- **Capacity Building**
- **Agility**
- **Trusting Relationships**
- **Communication**
- **Humility**



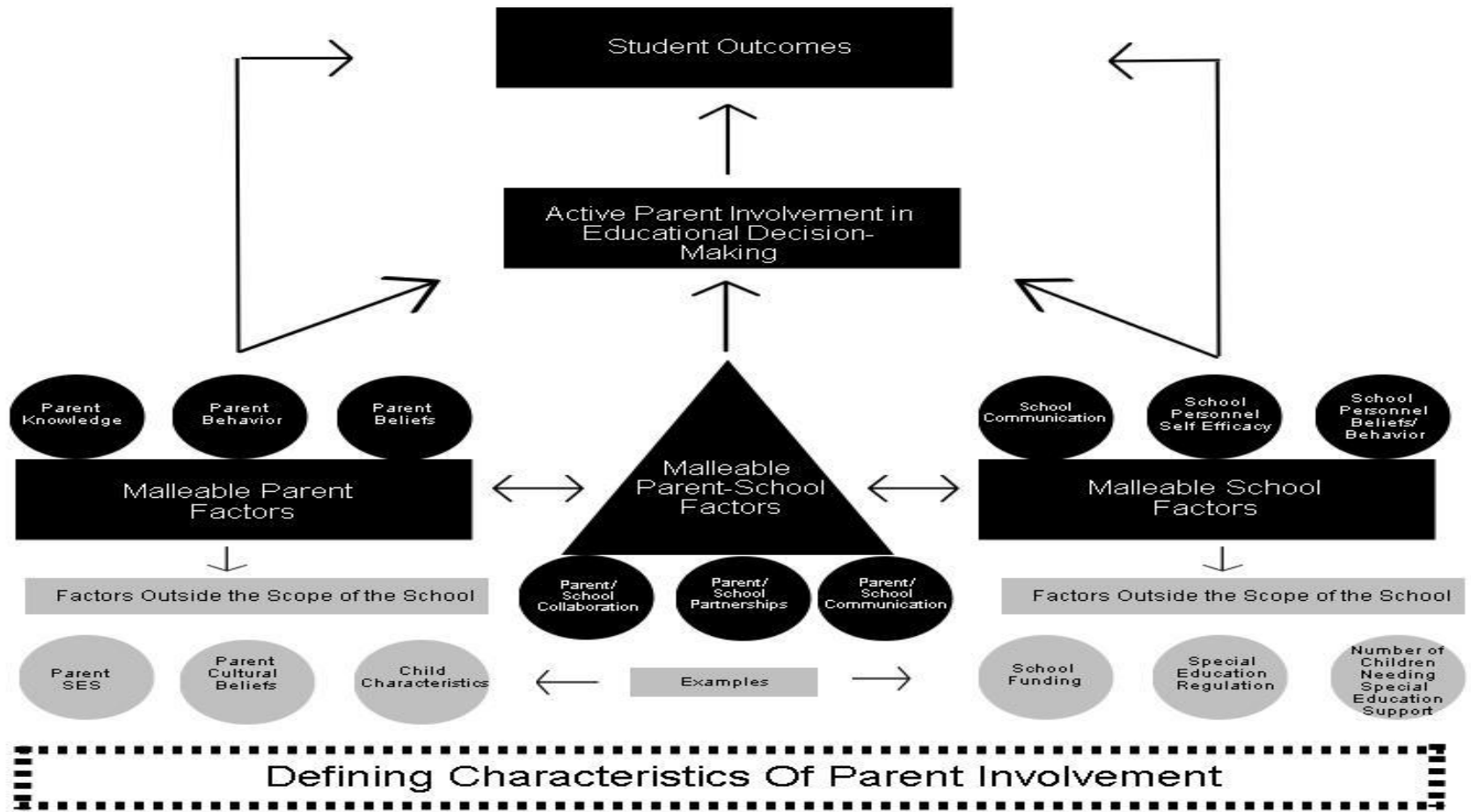
# Capacity Building



# Capacity Building

- To understand how families enter into relationships with schools/community agencies, we need to appreciate
  - how each parent takes in information,
  - what and who are their trusted resources, and
  - ultimately what factors most impact their decision-making

## Parent As Active Decision Makers with Schools



## Things We Can Change (Parent)



- **Knowledge**
- **Behaviors**
- **Beliefs**

Things We Can  
Change  
(School/Agency)



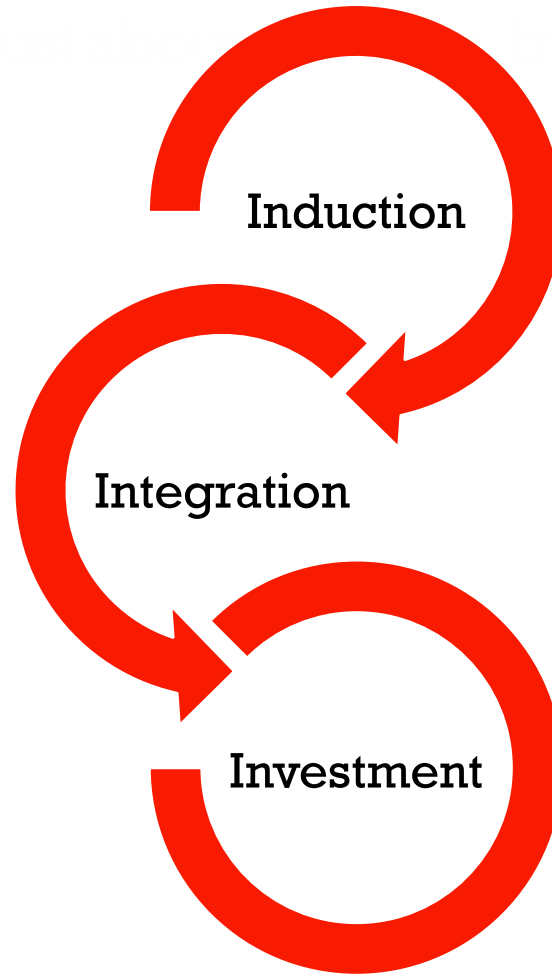
- **Teacher confidence**
- **Behaviors**
- **School communication**



Things We Can  
Change (Parent-  
School/Agency)

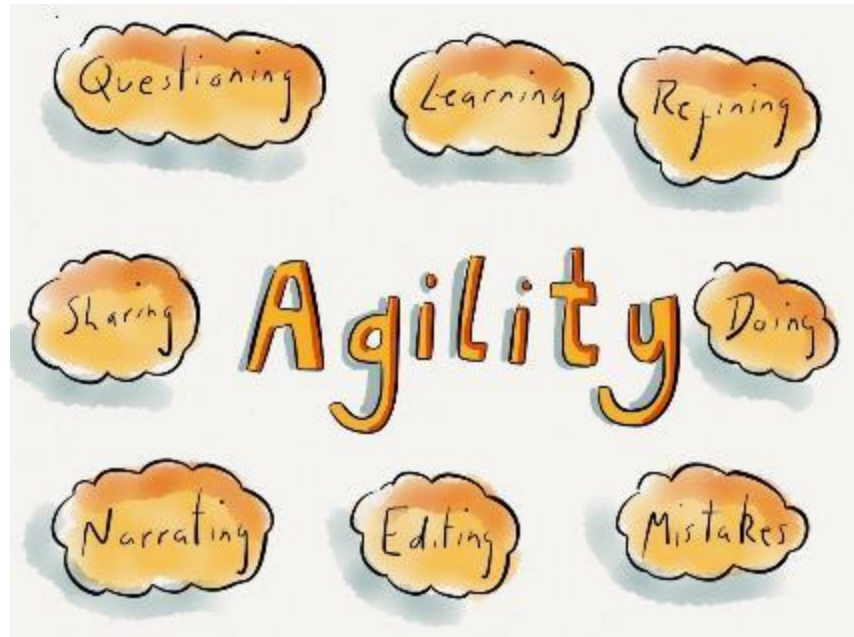


- **Collaboration**
- **Communication**
- **Partnering**

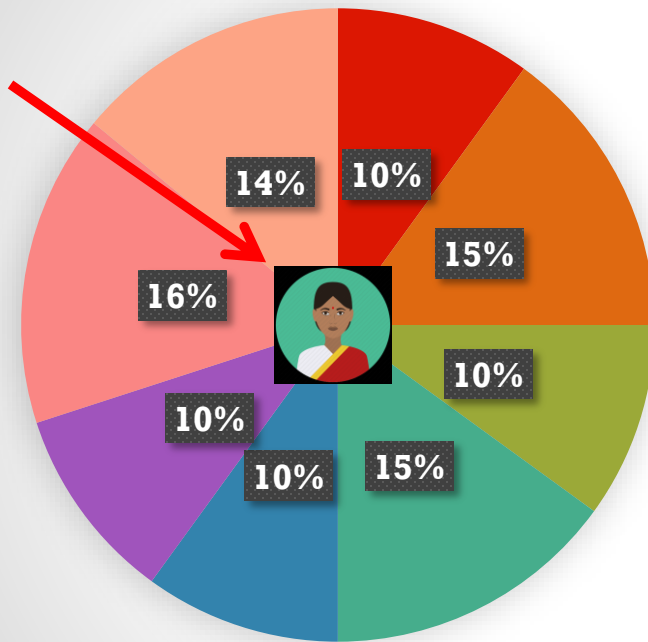


Source:  
Hong, S. (2012)  
A Cord of Three  
Strands: A new  
approach to parent  
engagement in  
schools

# Agility



This is where  
the family  
wants to be  
met.



- Disability
- Social Economic Status
- Sexual Orientation
- Gender Identity
- Patient
- Religion
- Race
- Ethnicity

Being culturally agile is about giving careful consideration to **your own assumptions and beliefs** that are embedded in your goals for the student/family.

Rather than learning to identify and respond to sets of culturally specific traits (stereotyping), a culturally agile person 'interviews' the family and **explores similarities and differences between his/her own and the family's priorities, goals, capacities and approaches.**



Cultural  
Agility

A hand is shown holding a globe of the Earth. The hand is positioned as if supporting the globe from below. A large, semi-transparent red rectangle is overlaid on the hand and globe, containing white text. The background of the slide is a light gray with faint, curved white lines in the corners.

## Cultural Agility Requires

**Lifelong commitment to self-evaluation and self-critique**

■ **Fixing power imbalances**

■ **Developing partnerships with people and groups who advocate for others**

## Trusting Relationships

**A relationship without trust is like a car without gas you can stay in it all you want, but it won't go anywhere.**

## Co-Powering

# POWERING POSSIBILITIES

- **Co-powering seeks to lift the confidence and energy of another person, yourself and the relationship**
- **The better we become at co-powering, the more we grow deeper relationships that develop our power to create positive personal, family and community change**



Communication

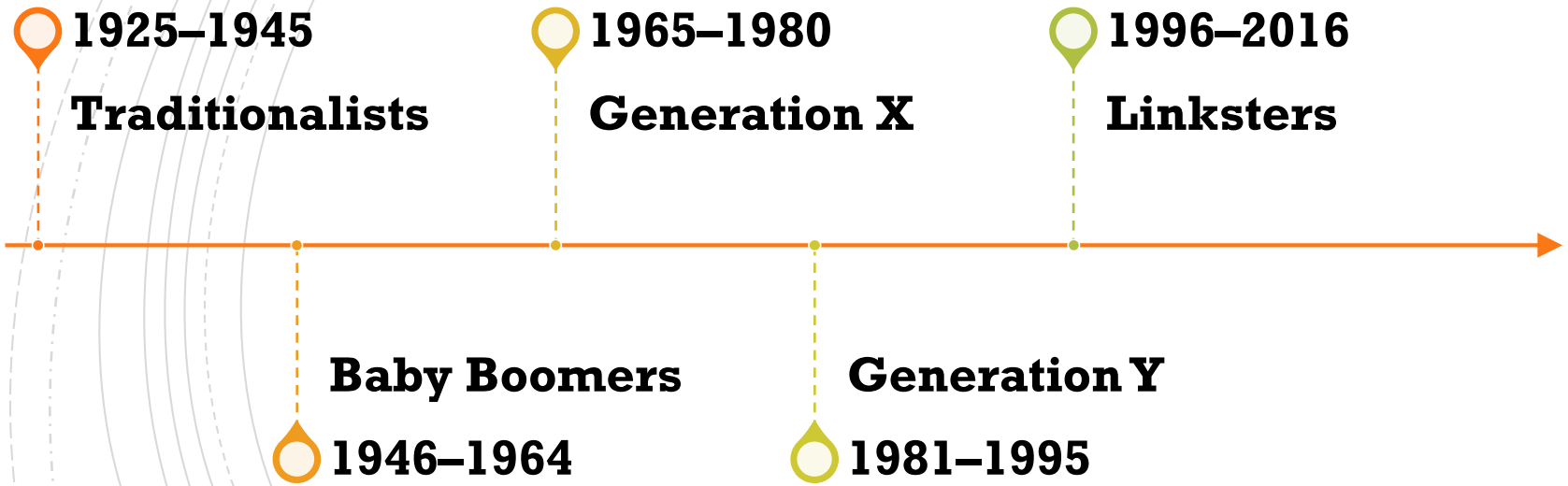




# Generational Communication

**From Traditionalists to Linksters**

## Generations defined



# Humility

true humility is  
staying teachable,  
regardless of how  
much you  
already know



## Having Difficult Conversations

Create a culture of safe climates for conversations

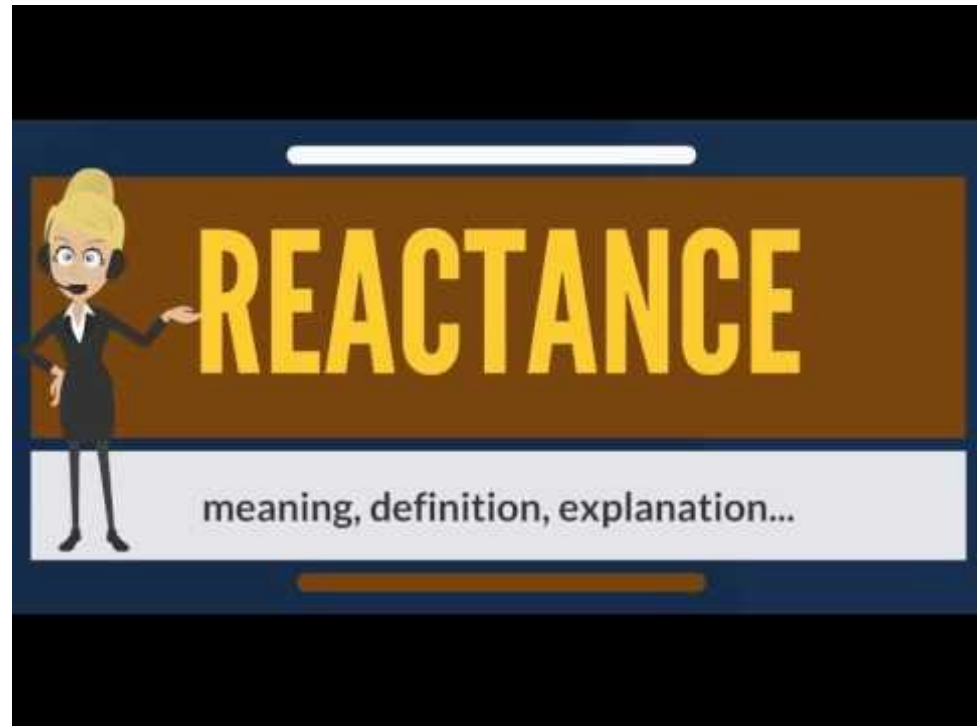
- B – boundaries
- R – reliability
- A – accountability
- V – vault
- I – integrity
- N – non-judgmental
- G - generosity



Stepping into the VOID

# Reactance Theory

Resistance is a normal or expected response to a lost or threatened personal freedom



# The Imperative to Communicate!

Susan Yuan, Ph.D.  
Center on Disability and Community Inclusion  
University of Vermont

# The search for intelligent life in the Universe





# Discovery



# Flashes of intelligence: OMG phenomenon!

- Fleeting, easy to miss
- Subtle
- Unique
- Creative
- Generalized
- Persistent

# Communication is an innate desire for connection!

- Response to crying
- Touch
- Eye contact

# Tools of Discovery

- Structured Observation for Discovery
  - Easy to assume nothing going on—because subtle
  - Fades into the background of everyday life
  - Choose a time you can observe without interacting
  - Write down every observable action
  - Look for patterns
  - Is the behavior a response to something happening?
  - Does the behavior appear to be generated by the child?
  - Continue to observe and write for as long as possible
  - Listen to vocalizations—what sounds does he have and how does he use them?

# Tools for Discovery

- Serendipity Enhanced by Positive Expectations
  - A Mindset of awareness and watchfulness
  - **Presuming Competence**
  - Recognizing, acknowledging and celebrating

# Tools for Discovery

- Tapping into shared memory pools
- Important to tell the person that you have the same memory; otherwise it can reinforce the idea some may have that you can read their mind!
- Build on the shared memory by further reminiscing

# Tools for Discovery

- Opportunities for readiness for Literacy
  - Talk constantly to them
  - Sing often
  - Nursery songs with gestures
  - Cultivating their musical taste
  - Reading to them
  - Good educational TV, especially with captions
  - Translate their sounds into words and identify that you understand them
  - Don't be afraid of exposure to more than one language. Bilingual comprehension is good!
  - School inclusion is best for modeling and exposure

# Tools for Discovery

- Discovery of preferred communication system
- Total Communication approach (whole communication)
- Validate **all** communication, at the same time you introduce other ways to communicate
- Combine systems—signing and saying the words
- Opportunities to point to word choices—but you should deliver on their choice
- Explore communication devices—but iPad is “cool”.
- If Facilitated Communication or Supported Typing is an option, try to get it introduced and coached by someone who knows what they are doing!
- Encourage creativity by teachers. Let them do what they do best—teach and discover.



# Overcome resistance

- Communication can be hard work. Make it fun if you can, but be persistent.
- Overcome the “path of least resistance.”
- Structure time to concentrate on building skill.
- Advocate constantly for opportunities.
- Don't be discouraged by skeptics with low expectations.

# Right to Communicate Initiative

- AUCD in collaboration with others
- Advocating for funding for a National Resource Center on Augmentative and Assistive Communication (AAC)

# Values

- Nothing about us without us.
- Everyone communicates.
- The Communication Imperative—Communication is a human right.
- Working across diagnostic labels
- Equity—Communication for ALL
- Accelerating progress

# A Framework for Supporting Individual & Family Engagement at the Systems-level



AUCD Conference: *We All Belong Here. Achieving Inclusive Communities*

Washington, DC

November 13, 2018



# Support for this work



**Lucile Packard Foundation**  
*for* Children's Health

# Family Voices



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

# Family Engagement

## Individual

Patient/Family-  
Health provider

## Advisory

Surveys, focus  
groups,  
committees

## Shared Leadership

Policies, Programs,  
Practices, Services

# Lit Review & Key Informant Interviews

**FAMILY VOICES**  
Literature Review  
Framework for Assessing Family Engagement

**VISION**

**Introduction**  
Families of children and youth with special healthcare needs (CYSHCN) best understand the issues and complexities of care systems because they are involved with all aspects of these systems. As their children's primary caregivers, they are personally affected by systems issues. This unique experience makes families key partners in shaping healthcare policies and programs (HRET, 2015; Kuhthau et al., 2011; Funchess, Spencer & Narhos 2014; Howrey et al. 2015; Reynolds et al., 2015).

As home to the National Center for Family/Professional Partnerships, Family Voices is an integral component of the Maternal-Child Health Bureau's commitment to authentic patient and family engagement (Krauss et al., 2001; Anderson & Wells, 2001; Wells & Anderson, 2006) AMCHP, 2016) and a long history of efforts undertaken to understand and implement elements of family engagement at the systems level to improve services, programs and policies around children's health. For this literature review, we draw on literature from a variety of sources, within and without the maternal child health community, including peer-reviewed articles and grey literature reports. The articles and reports reviewed represent wide ranging and sophisticated approaches to patient and family engagement being practiced today, and provide a picture of a vibrant and increasingly evidence-based field of study.

Healthcare systems serving children and youth with special healthcare needs will support effective strategies that place the family at the center of all levels of healthcare and will be strongly motivated and prepared to work collaboratively with families to implement.

**HealthInsurer**  
**LEND**  
**Medicaid**  
**HospitalStaff**  
**GovernorAppointedAdvisoryCommittee**  
**TitleV** **FamilyLeaders** **DPH**  
**RGN** **Professionals**  
**FamilytoFamilyHealthInfoCenter**  
**PediatricProviders**  
**SteeringCommittee**



# Framework for Family Engagement



April 2018

## Issue Brief: A Framework for Assessing Family Engagement in Systems Change

*by Clarissa Hoover, MPH, Mary Jo Paladino, MSA, Beth Dworetzky, MS, and Nora Wells, MEd*

### Abstract

Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care because they are involved with so many aspects of these systems. As their children's primary caregivers, families are deeply affected by systems-level issues, such as care fragmentation, which are often a direct result of ineffective or outdated health care policies and practices.<sup>1</sup> Families' lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially CYSHCN.<sup>2,3,4,5,6</sup>

<https://www.lpfch.org/publication/framework-assessing-family-engagement-systems-change>

# Systems-level Initiatives

- **Policy:** Add a new service to the state Medicaid program
- **Program:** Create a Youth Advisory Council
- **Practice:** Agency staff and families co-train to build leadership and partnership skills
- **Service:** Respite services

# Family Engagement

*Authentic partnership between organization staff, families, youth and young adults who reflect the diversity of the communities they represent, working together at the systems level to develop and implement better policies, programs, services, and practices.*

# 4 Domains of Family Engagement

**1) Commitment**

**2) Transparency**

**3) Representation**

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**4) Impact**

# Domain 1: Commitment



- 1) All partners (family leaders and organization staff) make themselves available to work together in good faith towards accomplishing a systems-level initiative.
- 2) Family engagement is promoted as a core value of the organization.
- 3) Family engagement is explicitly included as part of systems-level initiatives that impact the organization's policies, programs, practices, services, or other initiatives.

# Commitment: Key Criteria

Does the organization:

- Provide mentoring/supports to ensure families understand their role and can participate as fully as possible?
- Engage families in developing its strategic plan, mission statement, grant applications, and other programmatic documents (example Block Grant Application/Report)?
- Describe family contributions in written reports, and other publications?

# Domain 2: Transparency



Occurs when the organization clearly documents and communicates about how it:

- 1) Identifies the issues encountered by the children and families they serve.
- 2) Supports and engages families as leaders in the organization's policy, program, service, or practice initiatives.
- 3) Ensures that family leaders can easily access and understand the information they need to participate effectively in systems-level initiatives.

# Transparency: Key Criteria

Does the organization:

- Conduct specific activities to understand the issues faced by the children and families they serve?
- Provide skill-building opportunities to support all participants in their partnership roles?
- Provide training to ensure all participants learn to recognize, understand the impact of and reduce personal biases?
- Provide materials in plain language?
- Ensure meeting times and locations are convenient for family leaders?



# Domain 3: Representation

Occurs when family leaders reflect the diversity of the community served by the organization when they represent their community in systems-level activities.



# Representation: Key Criteria

Does the organization

- Collaborate with a family-led or community-based organizations to recruit family partners?
- Engage family partners who are representative of the
  - Races and ethnicities
  - Cultures
  - Languages
  - Disabilities
  - Ages
  - Genders
  - Geographic area served by the organization?

# Domain 4: Impact



Describes the areas where family leaders' ideas and views were incorporated at the systems level to improve policies, programs, practices, and services.

# Impact: Key Criteria

Does the organization:

- Engage family partners in choosing goals?
- Engage family partners in implementation?
- Engage family partners in evaluating new policy, program, practice, or service?
- Make decisions based on family partners' ideas?
- Explain how policies, programs, practices, or services have changed because family partners were engaged in the initiative?

# Any Questions?





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A word cloud of expressions for "thank you" in various languages. The most prominent words are "thank you" in red, "gracias" in green, and "merci" in orange. Other visible words include "danke", "spasibo", "dziękuje", "obrigado", "sukriya", "kop khun krap", "arigato", "takk", "dakujem", "merci", "ngiyabonga", "tesekkür ederim", "dank je", "moichchakkeram", "go raibh maith agat", "kop khun krap", "arigato", "takk", "dakujem", "merci", "ngiyabonga", "tesekkür ederim", "dank je", "moichchakkeram", "go raibh maith agat", "kop khun krap", "arigato", "takk", "dakujem", "merci".

