

#### Who We Are

Presenters

Programs

· Connecticut Birth-to-Three

## Who are you?

- Parent
- · Teachers of the Deaf
- · SLP
- Administrator
- State Agency
- Audiologist
- Nurse
- Doctor



#### Goals

- To identify challenges to effective communication
- To understand a mindset and guide to improve communication

Background information

Influences on the family

Influences on the provider

Suggestions

Discussion

#### NO CHECKLIST!





Sometimes it's the journey that teaches you a lot about your destination

Drake



## Background

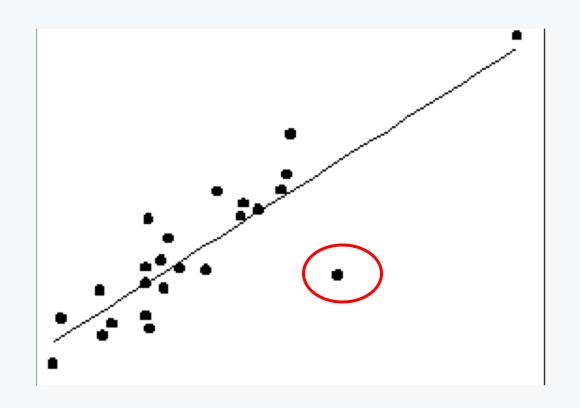
Case studies

Articles

Books

Yoga Class

## WHAT KEEPS US UP AT NIGHT?



## Facts are stubborn, but statistics are more pliable

Mark Twain

# What are the roadblocks that you have experienced?

## Barriers/Challenges to Effective Early Intervention

#### Societal Barriers

- Work/Employment obligations
- Distance to services
- Access to resources (or lack of)
- Social media/connectivity
- Lack of supports
- Misinformation (public and family/friends)
- Professional divisiveness in and out of the profession

#### Family Support

- Commitment to process/long-term outcomes
  Extended family — sabotage/guilt
  Lack of support system
  Isolation

- Shortage of interpreters

#### Attitude & Perception of Hearing Loss

- Parent acceptance/denial/quilt
- Fix it now"/"Fix it later"
- Learned helplessness
- Personal responsibility

#### Family Lifestyle/Culture

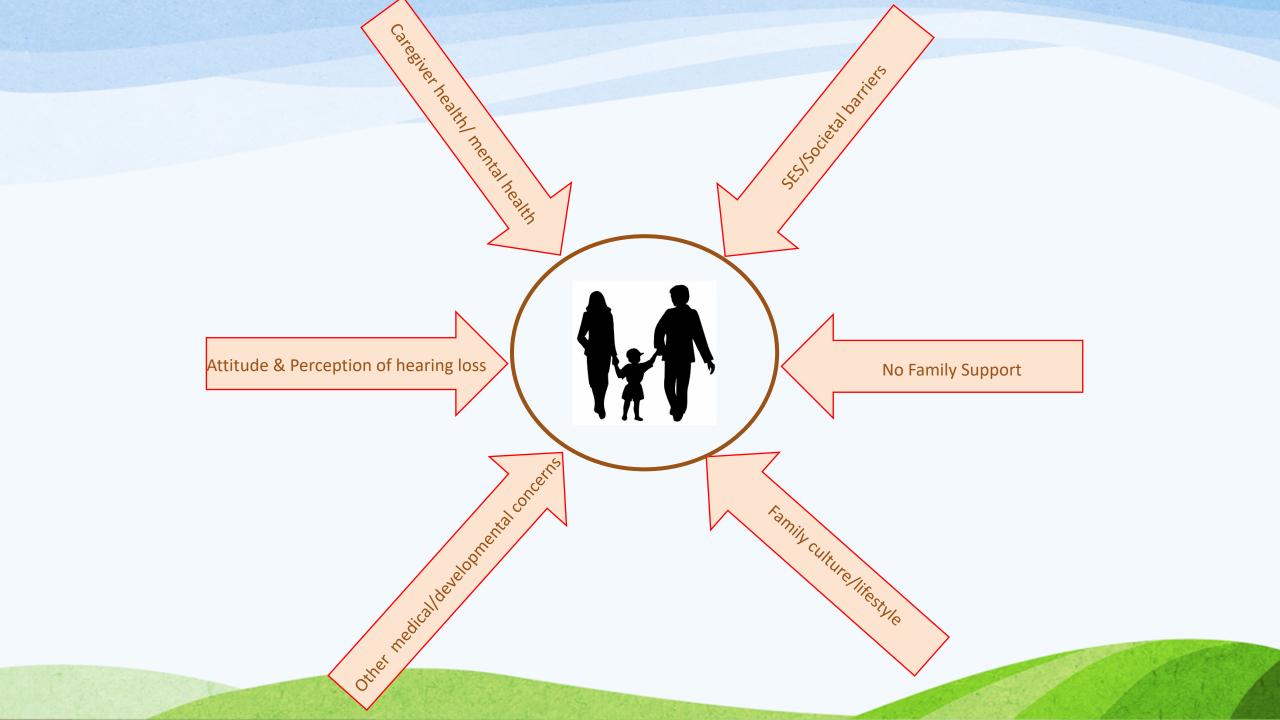
- Lack of trust
- Leap of faith
- Other family obligations
- Family priorities
- Cultural morays/Cultural perception
- Religion/culture/status
- Adult learning styles
- Loss of control

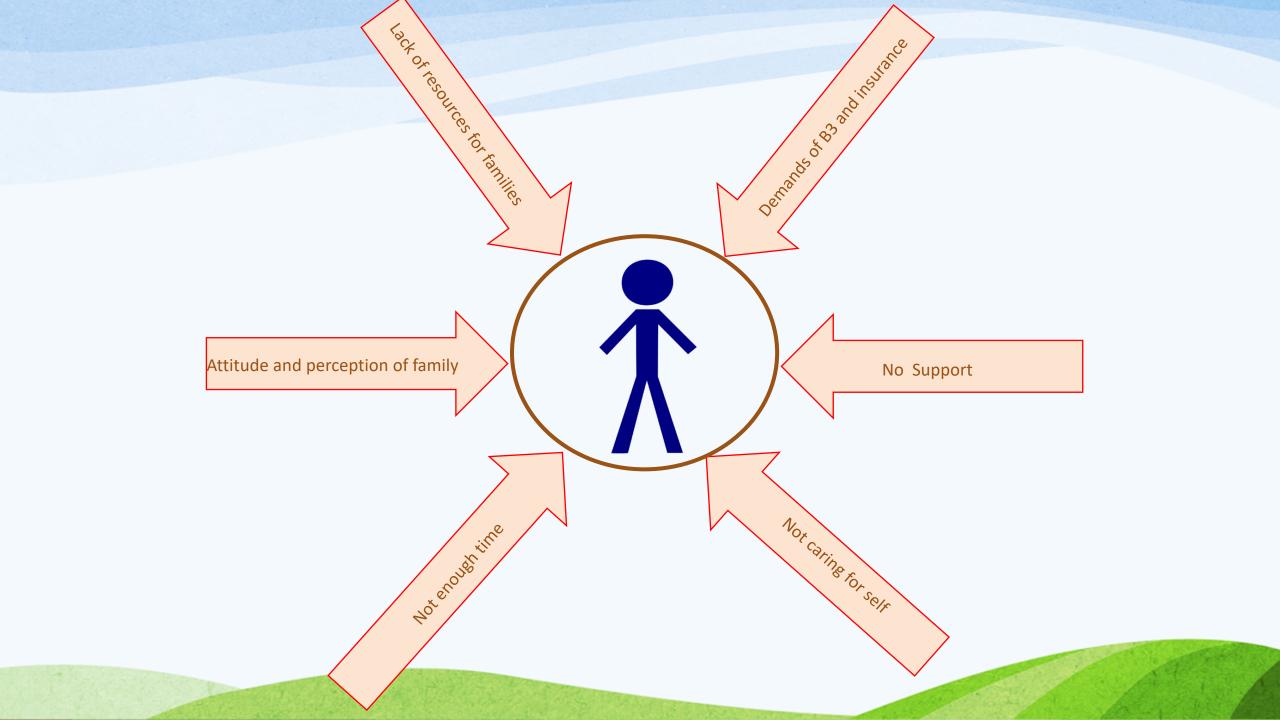
## <u>Caregiver Health/</u> <u>Mental Health</u>

- Depression
- Anxiety
- Acute or long-term illnesses
- Bonding
- Isolation
- Resilience (lack of)

#### Other medical/ developmental concerns

- Late diagnosis
- Other medical diagnoses
- Emerging developmental concerns
- Genetics
- Unforeseen complications
- Medically complex





#### FACTS TO CONSIDER ...

- The US Census Bureau 2015 estimates indicate that 50.3% of children younger than 5 were racial or ethnic minorities in 2015.<sup>1</sup>
- There were 13,253,000 children living in poverty in 2016.2
- The number of children under 5 living in poverty: 3,810,000.2
- The percent of all poor children living in single-mother families: 59.5 percent; in single-father families: 8.0 percent; and in married-couple families: 32.5 percent.<sup>2</sup>
- Early Head Start in CT had enough funding to provide services to 8% of those children who were eligible
- More than two-thirds of poor children (69.5 percent) had at least one family member who worked, and nearly one-third (30.9 percent) had at least one family member who worked full-time year-round.<sup>2</sup>
- While Black children had the highest poverty rate, the largest number of poor children were Hispanic children (4,890,000) followed by White children (4,050,000) and Black children (3,135,000).<sup>2</sup>

http://www.pewresearch.org/fact-tank/2016/06/23/its-official-minority-babies-are-the-majority-among-the-nations-infants-but-only-just/http://www.childrensdefense.org/library/data/child-poverty-in-america-2016.pdf

#### FACTS ABOUT HEARING LOSS

- There are an estimated 15 million people in the United States with hearing loss.1
- About 87% of those children who are d/hh were referred for early intervention services.<sup>2</sup>
- The prevalence of hearing impairment at all ages decreases as family income increases. Overall, those with a family income of less than \$10,000 are twice as likely as those with a family income of \$50,000 and over to have hearing impairment.<sup>3</sup>
- In the lowest family income group, 1.72 children in 1,000 were born with hearing loss. In the highest socio-economic group, just 0.47 children in 1,000 were born with hearing loss.4
- A child who is deaf or hard-of-hearing is more likely to be of poorer health, more likely to have Medicaid, to live in a single-mother household and to live below the poverty line.<sup>5</sup>

World Health Organization, 2018
 https://www.cdc.gov/ncbddd/hearingloss/data.html
 https://www.ncra.org/Government/content.cfm?ItemNumber=9450
 https://www.hear-it.org/hearing-loss-more-widespread-among-those-less-well-off
 Boss EF, Niparko JK, Gaskin DJ, Levinson KL. Socioeconomic Disparities for Hearing-Impaired Children in the United States

## Paying Attention



- · What were the words telling you?
- What did the body language tell you?
- What might be helping this person learn something from this presentation?
- What might be getting in the way of this person learning something from this presentation?
- What could I do on the second day of this presentation?

## Learning from every family

- I like when you come to my home BUT every visit is a reminder that I have a child with special needs
- Don't take out that checklist; I know my child has delays.
- My husband is embarrassed to take our child outside so he takes off the BAHA.
- I need food. I need a job. I need money.

- I feel as though I was cheated out of the happiness of the birth of a baby. All my friends who have babies are happy.
- Using the community to provide what the child needs.
- Why am I being punished?
- I am praying that \_\_\_\_ fixes my child.

#### As Individuals

- What does this family need today?
- Park your judgments and baggage with your car
- Be present and attend
- Reflect with the parent at the end of the session

- Before you can be kind and compassionate to others, you have to first and foremost be kind and compassionate to yourself.
- Take time to reflect on the session both on and below the surface
- The IFSP rarely represents the reality of the whole picture

## Collectively

- Demand that teams be given time to meet to review cases and to support each other
- Pool resources
- Take time to reflect with your team on successes but more importantly the struggles



## Institutionally

- Use attention, compassion and awareness as the demands of a medical model take hold
- Advocate for change in your states by getting onto task forces and coalitions
- Support legislation by testifying, writing letters and going to the Hill

- Join professional organizations nationally
- Join together as a profession to make sure the needs of families are being met

"

# I have an existential map. It has "you are here" written all over it.

Steven Wright, comedian

"

#### FUN FACTS!

- Colorado and Connecticut both start with "CO."
- The governor of Colorado graduated from Wesleyan University in Middletown, CT.
- State minerals of CO and CT are both red!
- Both states were named after their rivers!
- What else connects CO and CT?

...a road

## It's a Road Trip....

• FROM CT TO CO TO ATTEND THIS CONFERENCE!

