



RESEARCH. ADVOCACY. AWARENESS.

AMERICAN COCHLEAR IMPLANT ALLIANCE

# Barriers to Early Hearing Intervention Services: What can we do to improve child and family access?



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# American Cochlear Implant Alliance

## *Unique Organization in Field*



- Membership organization concerned with access to care across the continuum of hearing loss
- Research, Awareness, Advocacy
- Membership: Audiologists, speech language pathologists, early interventionists, physicians, educators + others on CI teams, consumers + parents
- Key focus: Access to hearing healthcare and information on hearing health for people of all ages

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

<https://www.facebook.com/ACIALLIANCE.ORG>

<https://www.linkedin.com/company/acialliance>

# Learning Objectives

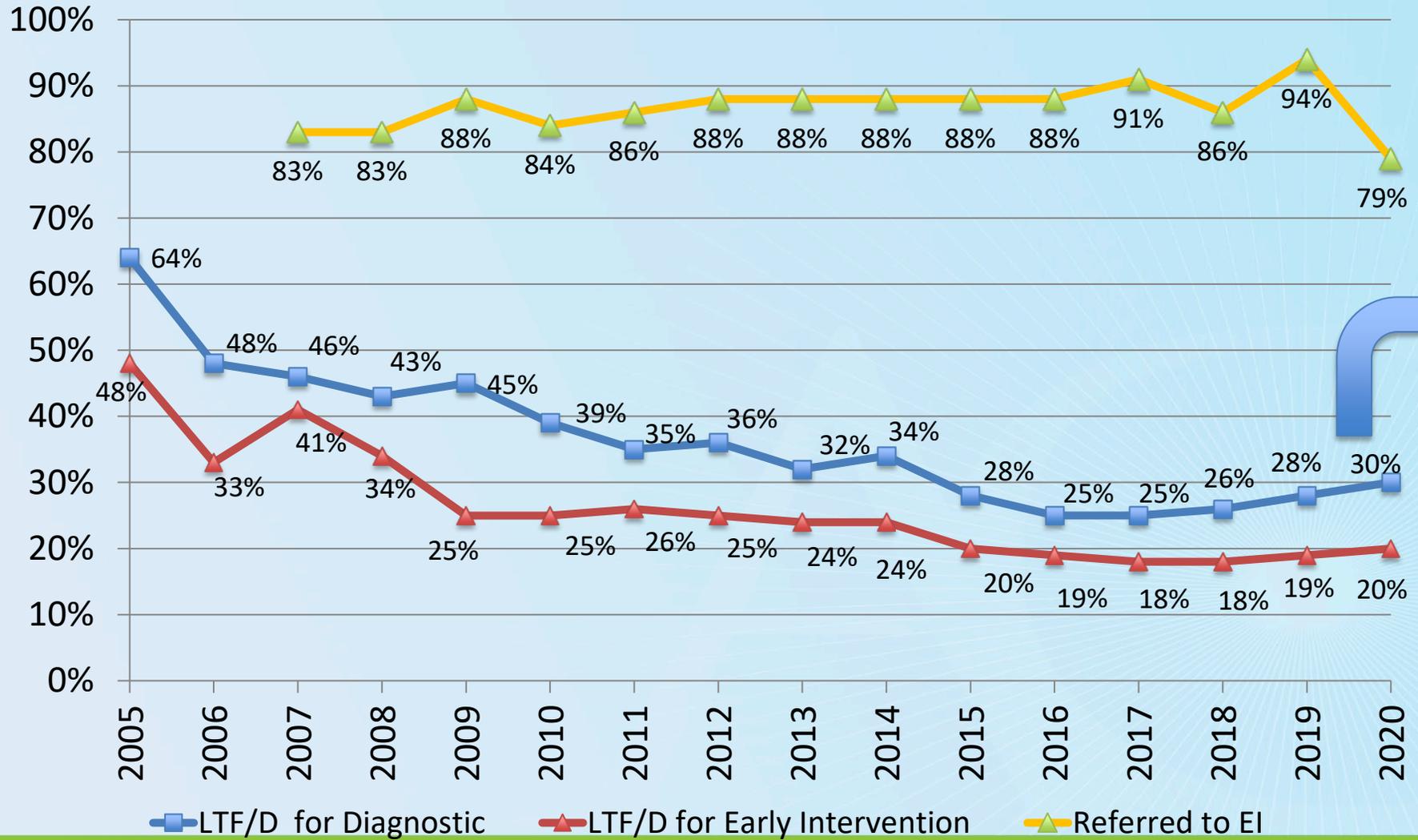
- Identify common medical provider barriers to timely provision of hearing care services for young children with hearing loss
- Review patient barriers that delay diagnosis or service delivery
- Discuss parent or family characteristics that complicate or impede initiation of early intervention services



# Provider Barriers



# Percentage of EHDI Children LTF/D for Diagnostic Testing, Referred to EI, and EI Enrollment in the US



**Access to Pediatric Audiologists**

- Rural Location
- Wait times
- Delay in Diagnosis

Credit: Karl White  
NCHAM

# Finding Appropriate Team Members can be the most challenging part of a family's journey for their young child

- **EHDI-PALS**

Web-based searchable national directory covering healthcare professionals and state public health organizations offering pediatric audiology expertise for children ages birth-5

- **Pediatric audiologists** often not in rural areas

- **Pediatric otolaryngologists** (hard to find)

<https://aspo.us/page/findanent>

– not very helpful as a directory resource

- **Otologists** have knowledge across hearing loss

- Variability in **pediatrician** knowledge

# Google: EHDI-PALS

## Find Hearing Services

For a list of audiology facilities in your area that will best meet your current needs, please complete the following questions:

1. What is your child's date of birth?

( required )

2. My child's immediate need (select one): (required)

Hearing Screening [i](#)

Diagnostic Hearing Test [i](#)

Sedated Diagnostic Hearing Test [i](#)

Hearing Aid Services [i](#)

Earmolds [i](#)

Cochlear Implant Services [i](#)

Not sure, but I am concerned about my child's hearing

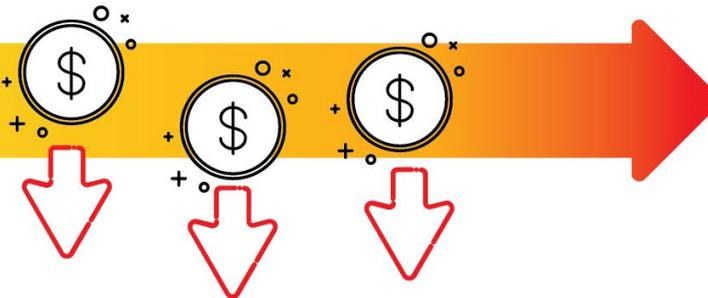
# Diagnosing a Child's Hearing Loss

- First step after a failed newborn hearing screen
- Typically done by a pediatric audiologist
  - Sometimes an ENT is involved
- Audiologists are now beginning to suggest genetic testing as part of diagnostics but still only 200 done per year at present
- Genetic screening is available at no cost to the family due to some new programs

# How does Medicaid Impact Early Intervention Access?



~50% children w/ hearing loss **covered by Medicaid for hearing related care**



Across states:  
**low, variable payment rates**

~~Medicaid~~

**Low reimbursement + high no shows**  
leads some providers to not accept Medicaid



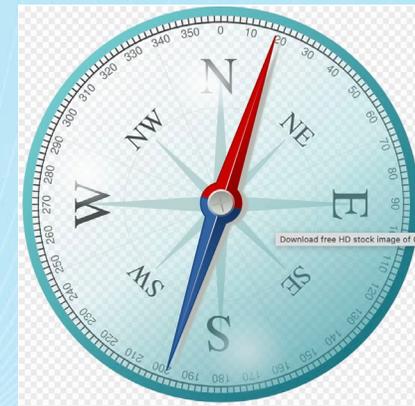
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# Recent Changes in Medicaid

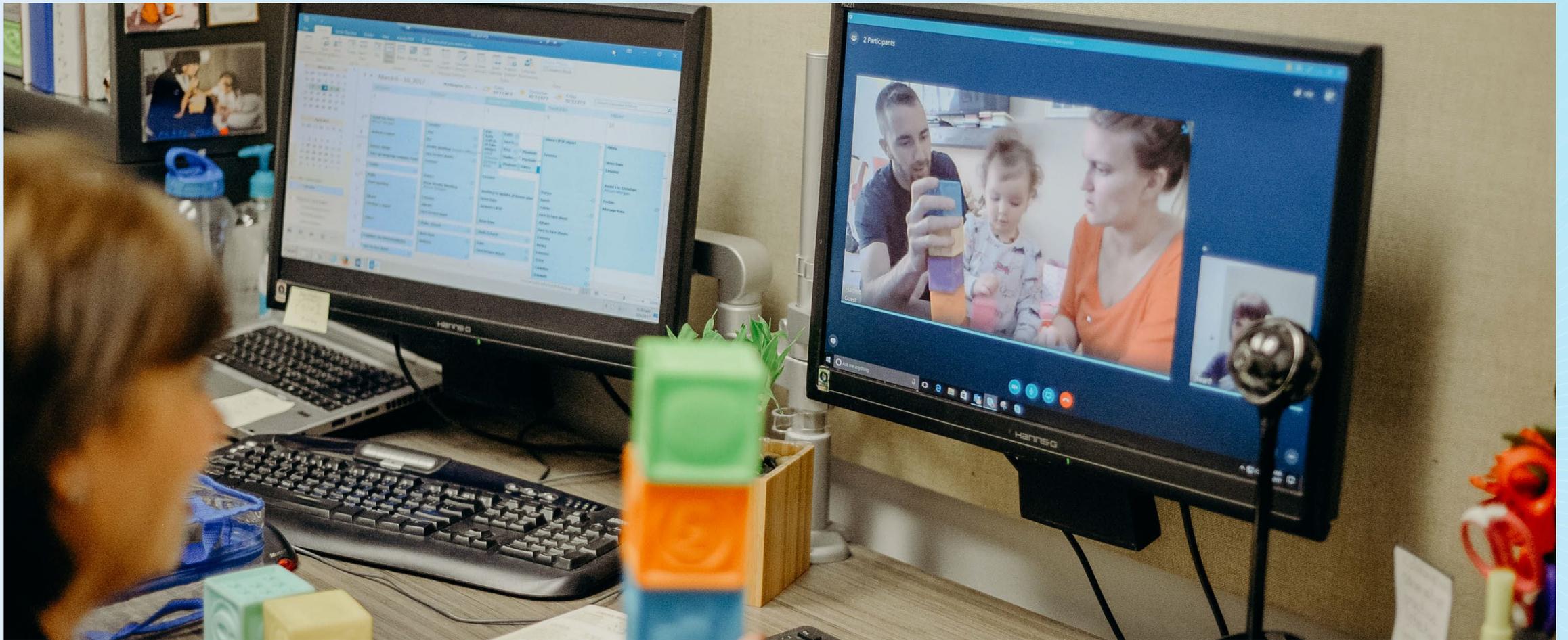
- Lower priority for Medicaid by current Administration
- Additional steps initiated for families to remain eligible
- Medicaid funded by states and federal government
  - Federal match amount depends on the state
- Cuts in Federal support likely to impact provider availability for services that are heavily Medicaid funded

# Patient Navigators

- Trained professionals (i.e., nurses, social workers, community health workers) who guide patients through complex health systems
- Act as advocates, schedule appointments, arrange transportation (Medicaid covers), coordinate with providers
- Covered by Medicaid and Medicare
- Sometimes covered by private insurance since 2024 when new billing codes were introduced (especially in hospital setting)



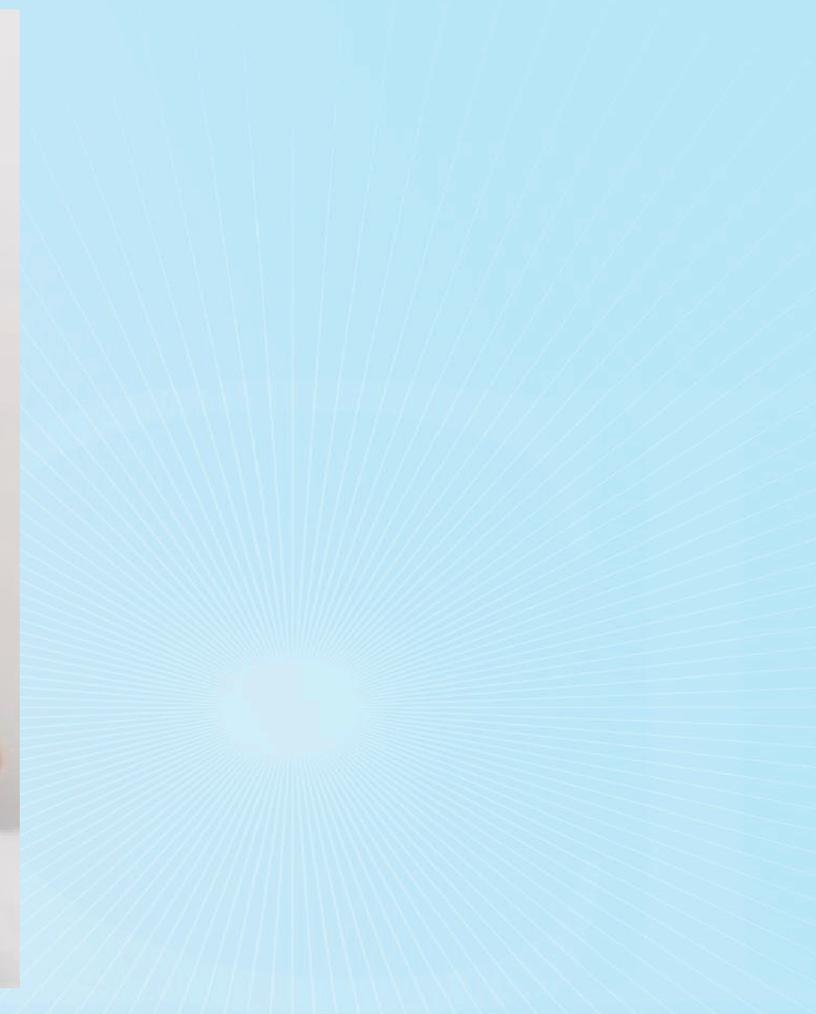
# Telehealth can help!



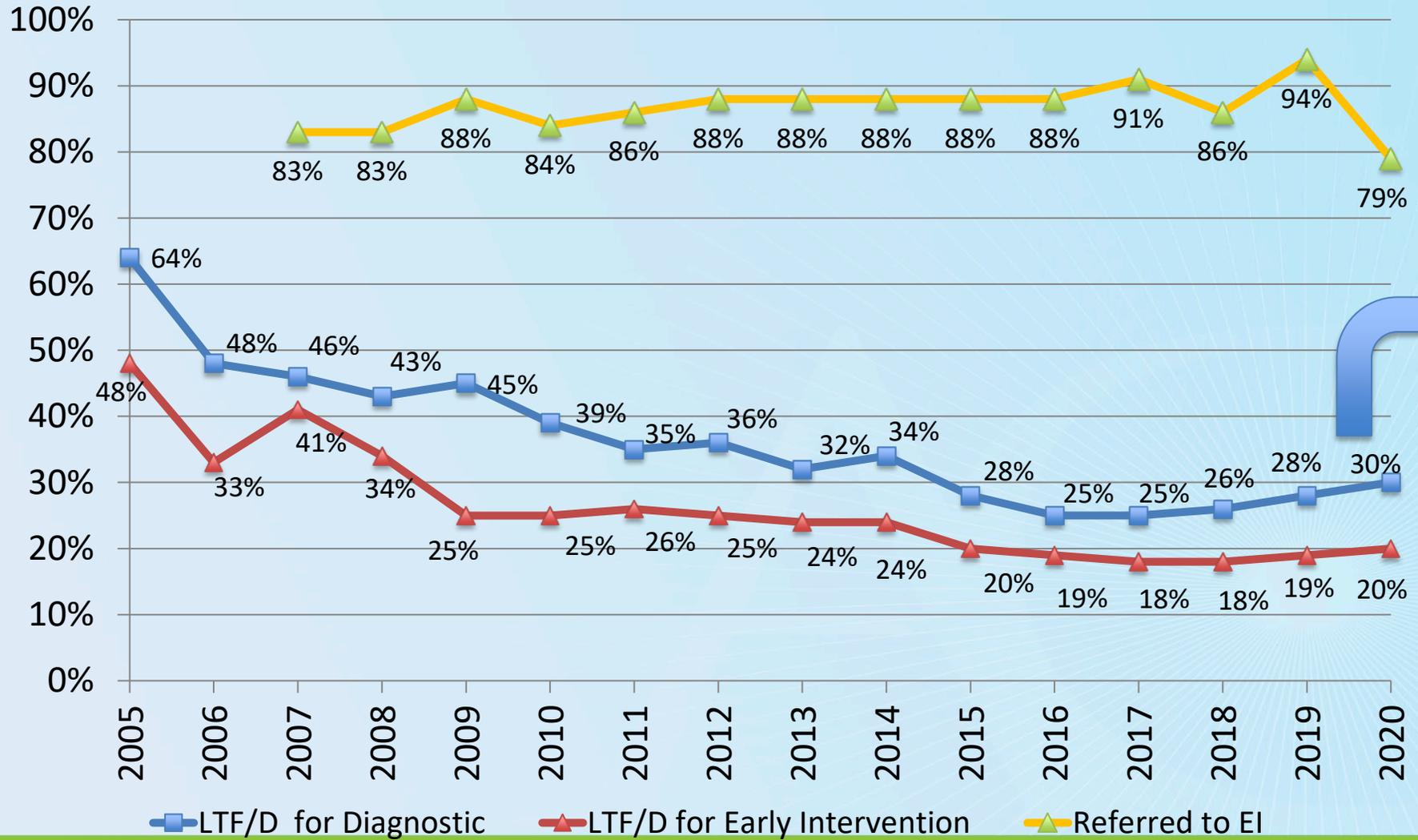
# Remote Therapy Providers

- **St. Joseph Institute for the Deaf** offers iHear teletherapy
  - Supports children & families in listening and spoken language
  - iHear teletherapy has provided more than 20,000 sessions worldwide to children 0-18 years old
- **John Tracy Center (Los Angeles)**
  - Distance appointments via live video allowing parents to interact with their child at home coached by LSL specialists
  - Range of professionals (audiologists, educators, SLPs, LSL specialists)
  - Parents can ask questions, explain concerns, share progress

# Patient Barriers (Child Characteristics)



# Percentage of EHDI Children LTF/D for Diagnostic Testing, Referred to EI, and EI Enrollment in the US



Does the child have other health issues?

- NICU stay
- Comorbidities: 30-40% do
- cCMV
- All above may delay diagnosis

Credit: Karl White  
NCHAM

# At least 40-50%\* with congenital hearing loss have other health issues or disabilities (*Wikipedia*)

- NICU
- Other Comorbidities (“Deaf+” / Deaf Plus)
  - Cognitive, physical, medical, emotional
  - Autism, cerebral palsy, vision impairment, ADHD
- cCMV leading cause of non-genetic HL
  - 20-25% of non-genetic HL (1 of 200 babies born with cCMV)
  - Total: 6-25% of permanent hearing loss (at birth and late onset)
  - Late onset CMV HL will often get missed in early weeks of life
- Other complication: Birth state NOT home state

# Mild and/or Unilateral Hearing Loss

- 20-30% of identified infants have unilateral HL
- Perception: Unilateral or mild or HL not an issue
  - Body of research shows otherwise
- More likely to send parents into denial mode
- Families may opt not to pursue technology or services yet...
- Child with untreated mild or unilateral HL:
  - 1/3 chance of failing one grade

## THE DEVELOPING CHILD WITH UNILATERAL HEARING LOSS

*A Guide to Early Intervention*



For Early Intervention Teachers of the Deaf/Hard of Hearing,  
Speech Language Pathologists and Pediatric Audiologists

By Karen L. Anderson, PhD

*A Supporting Success for Children with Hearing Loss Publication*  
<https://successforkidswithhearingloss.com>

# Single Sided Deafness (SSD) or Asymmetric HL

- Previously CI not used for SSD
  - Criteria previously were **bilateral** severe to profound
- This has changed though FDA criteria is still 5 years
  - Waiting 5 years does not consistently lead to most positive outcomes
- Some insurers will cover children at an early age

# ACI Alliance Task Force Guidelines for Clinical Assessment of Cochlear Implants (CI) in Children with **Single-Sided Deafness (SSD)**

- *At risk for hearing loss progression in better ear*
- *Dx bacterial meningitis*
- *Advantage of younger CI*
- *Developmental disadvantages of SSD due to difficulties with localization, hearing in noise, listening fatigue*
- *Auditory therapy strongly recommended*

[www.acialliance.org/page/DeterminingCICandidacy](http://www.acialliance.org/page/DeterminingCICandidacy)



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# Family Barriers

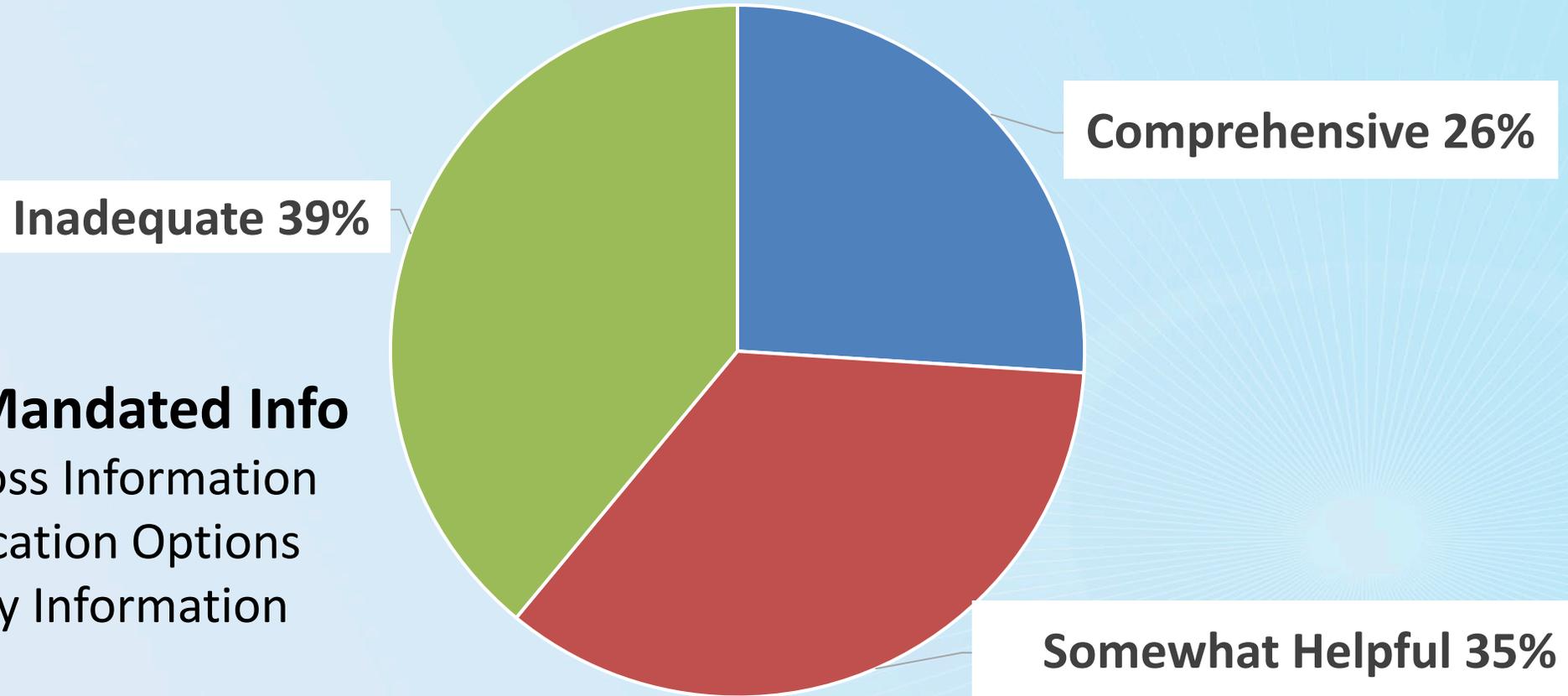






# Assessment of Information on State EHDI Websites

## Westin & Sorkin, JEHDI, 2021



### Federally Mandated Info

- Hearing Loss Information
- Communication Options
- Technology Information
- Resources

# EHDI Reauthorized

- 2008, 2017, 2022
- Bipartisan support each time
- **2017 Reauthorization added important language**

Information provided to families should be accurate, comprehensive, up-to-date, and evidence-based, as appropriate, to allow families to make important decisions for their children in a timely manner, including decisions with respect to the full range of assistive hearing technologies and communications modalities, as appropriate

- **2022 Reauthorization built on above language on parent info**

# Comprehensive, Unbiased Information



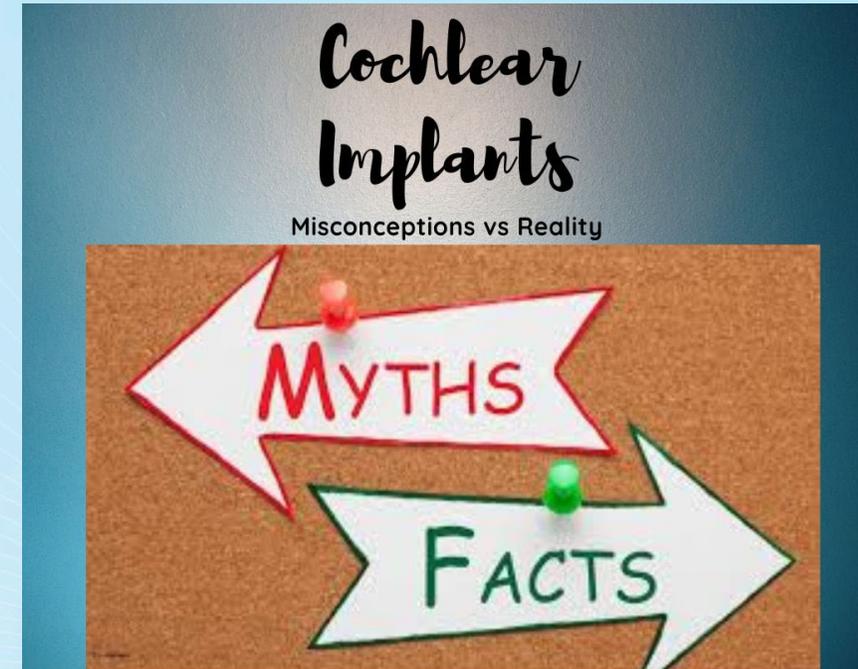
Parents do not consistently receive information about options for technology and communication

- **FY2023 Omnibus Act** encourages EHDI professionals to:
  - Work with partners to advance awareness about the wide range of modalities available for children who are deaf and hard of hearing
  - Specifically mentions auditory-oral therapy, auditory-verbal therapy, Signed Exact English, ASL, Total Communication, and Cued Speech
  - Also notes the full range of assistive hearing technologies that should be discussed including hearing aids and cochlear implants
- Not getting information in timely manner may delay fitting of hearing technology and impact outcomes
- 2023 bill highlights the need for full information and spells it out in the law but it is not happening everywhere

# How does information impact **EARLY** intervention?

## A: Myths, Misconceptions, Misinformation

- Bias about the “right” way for children with hearing loss to communicate
- Lack of understanding of the impact of early identification and old ideas about learning to listen with technology
- Low awareness + lack of understanding about benefit, candidacy, insurance, residual hearing, and its “ok to wait”



# Parent Understanding of Hearing Loss

- Acceptance—especially if it is “just a little hearing loss”
- Single sided deafness—not that big deal
- (S)he hears
- Subjective assessment based on observation
- Pediatricians don’t prioritize hearing loss
- Ensure they have a comprehensive picture of options

**= DENIAL**

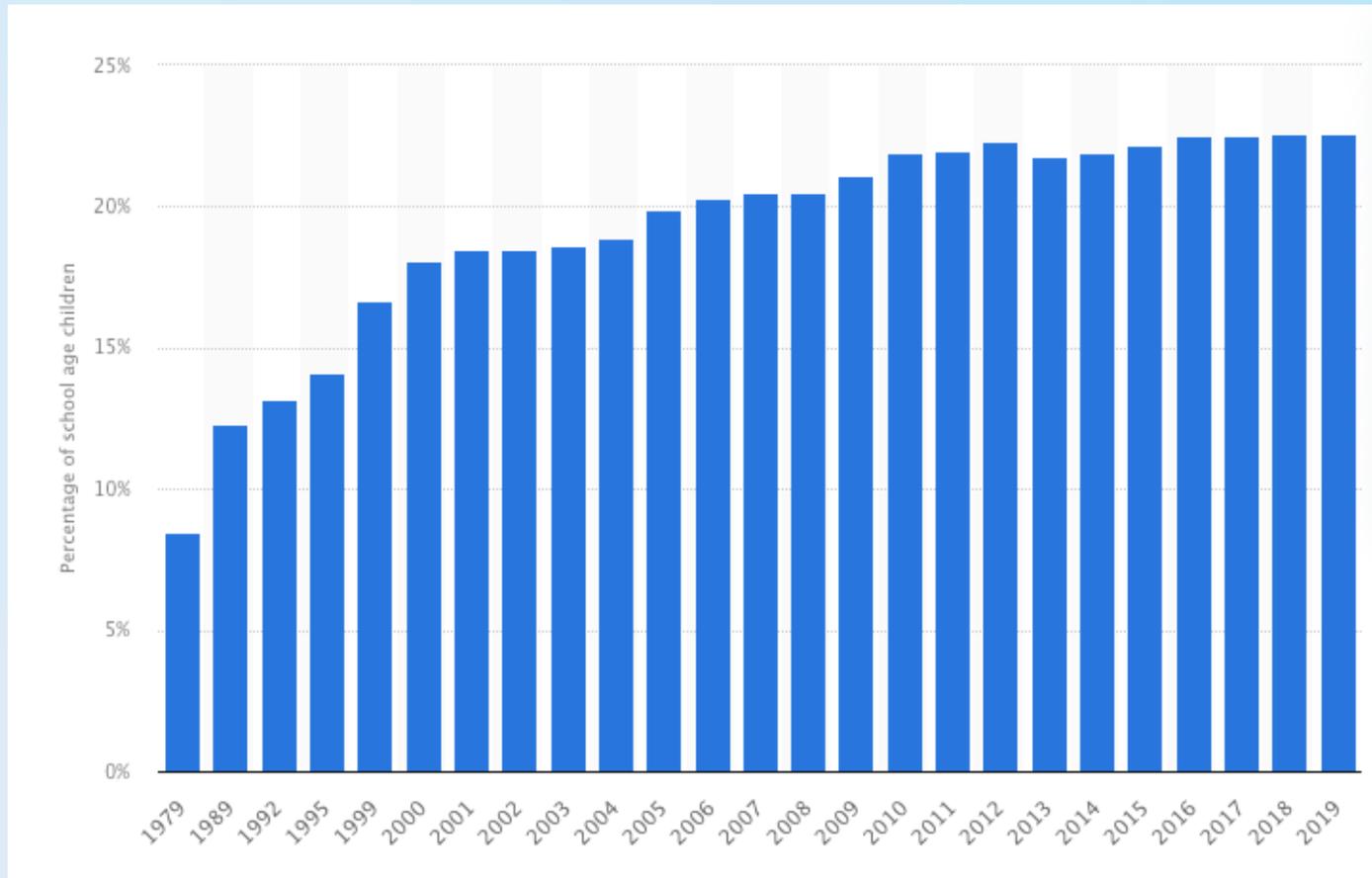
# Insurance and Other Barriers to CI Access



# Parent Stressors

- Ability to follow through on needed appointments
  - Workplace, distance
- Other family member needs
- Socioeconomic  Lower income, education, language of the home

# US Children (5-17) who Used a Language other than English at Home 2019: 22.6%



Expected to rise to 40% by 2030 (Annie E. Casey Foundation)

Source: Statista, Veera Korhonen, 6/2/2023

# Insurance and Childhood Hearing Loss

- More than 50% of young children with hearing loss are covered by Medicaid
  - Covers hearing aids, cochlear implants, audiology, habilitation
  - Many states cover children for health and disabilities regardless of family income due to EPSDT rules
- Private insurance *may* cover hearing aids; most cover CI for appropriate candidates
  - Typically covers CI and related audiology, habilitation, equipment
  - Not always a “slam-dunk” and parents may need to fight
  - Clinics and CI companies can help
  - Part C may help
- > 30 states have passed hearing aid mandated coverage for children
  - Amount reimbursed and frequency varies

## **If Child is Covered by Medicaid, support them:**

- Does provider accept Medicaid?
- Is reimbursement poor?
- Is there a wait to be seen?
- New rules instituted require more frequent certification and hurdles to overcome

## **Is Family in Rural Location?**

- More likely to have difficulty finding appropriate providers

# How Professionals Can Help Parents

- Provide research-based information in understandable formats
- Encourage parents to get help with insurance negotiation if a lack of coverage under EHDI or Part C and help with Medicaid as it will get more difficult in the coming year
- Introduce parents to other parents and to adults who can mentor and support
- Introduce patient navigators (under-utilized, billable support)

# Some Resources to Help Professionals & Parents

Organization	Website	Resources for parents	Resources for professionals	Resources for teachers
American Cochlear Implant Alliance	<a href="http://www.Acialliance.org">www.Acialliance.org</a> <a href="http://www.acialliance.org/page/resources">www.acialliance.org/page/resources</a>	X	X	
Hearing First	<a href="http://www.hearingfirst.org">www.hearingfirst.org</a>	X	X	
Supporting success for children with hearing loss	<a href="http://Successforkidswithhearingloss.com">Successforkidswithhearingloss.com</a>	X	X	X
American Academy of Audiology	<a href="http://www.audiology.org">www.audiology.org</a>		X	
American Speech-Language-Hearing Association	<a href="http://www.asha.org">www.asha.org</a>		X	