



These materials are Copyright © 2015 -2017 NCHAM (National Center for Hearing Assessment and Management). All rights reserved. They may be reproduced and distributed in print or electronic format at no cost to recipients and as long as full credit is given to NCHAM - including a link to the NCHAM site (infanthearing.org) and copyright notice (e.g., "© NCHAM").

Supporting the frontline responders: Providing accurate, useful information to family support organizations

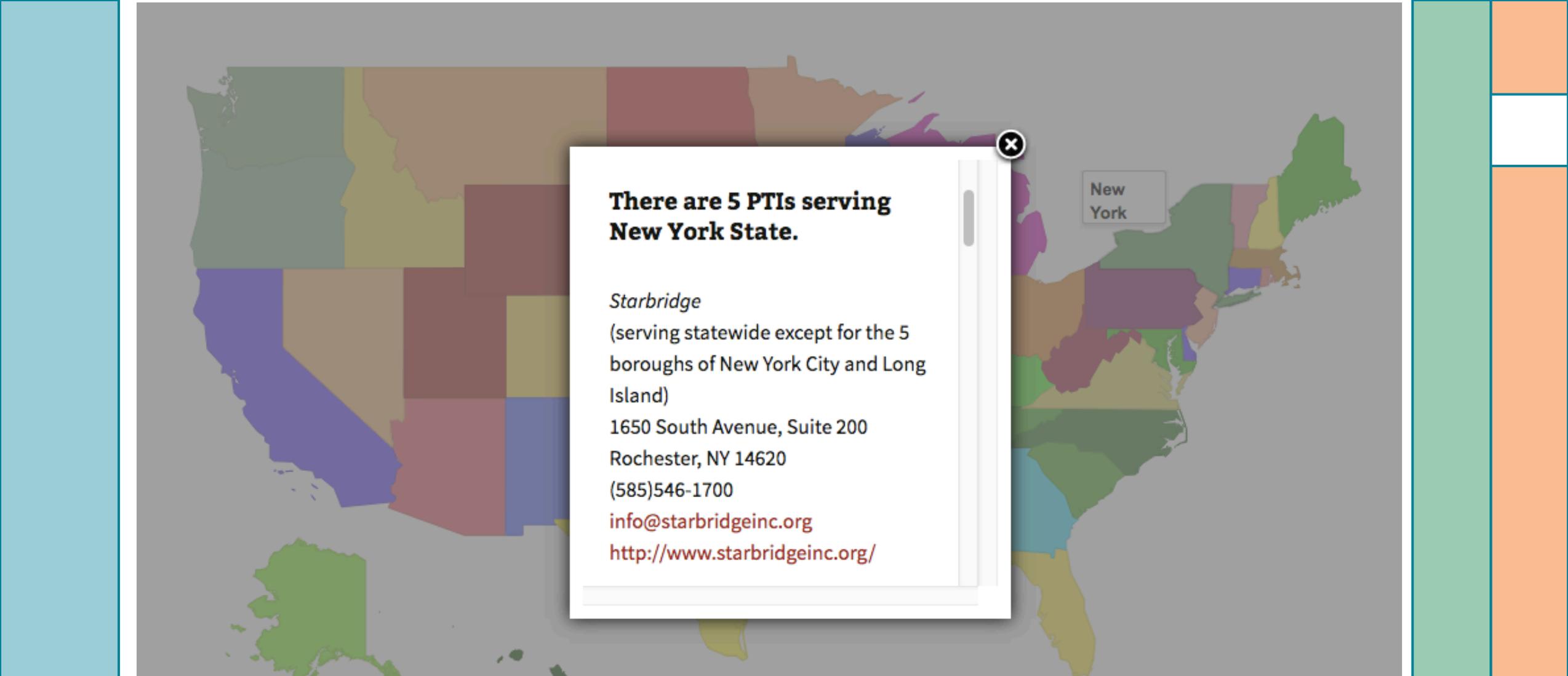
Sara Doutre, Diane Behl, Heather Mariger, Karl White

Early Intervention Systematic Nationwide Analysis of Programs' Strengths, Hurdles, Opportunities, and Trends (EI SNAPSHOT)

- › Funded by the Maternal and Child Health Bureau & Oberkötter Foundation
- › One year study looking at
 - Family reports and perceptions
 - Early intervention provider & audiologist reflections
 - **EHDI and Part C collaboration**
 - Deaf Education personnel preparation programs
 - Publicly available information for families

What are PTIs and CPRCS?

- › Parent Training and Information Center (PTIs) and Community Parent Resource Centers (CPRCs)
 - Are **family-led** organizations
 - Provide resources on **IDEA early intervention and special education** for parents of children with disabilities.
- › **Every state has at least one PTI.**
- › CPRCs focus on reaching underserved parents of children with disabilities.
- › **They are funded by the US Department of Education.**



**There are 5 PTIs serving
New York State.**

Starbridge

(serving statewide except for the 5
boroughs of New York City and Long
Island)

1650 South Avenue, Suite 200

Rochester, NY 14620

(585)546-1700

info@starbridgeinc.org

<http://www.starbridgeinc.org/>

<http://www.parentcenterhub.org/>

What are F2F HICs?

- › Family-to-Family Health Information Centers (F2F HICs)
 - Are **family-staffed** organizations
 - Assist families of children and youth with **special health care needs** and the professionals who serve them.
- › F2F HICs provide support, information, resources and training around **health issues**.
- › **They are funded by the Health Resources & Services Administration (HRSA).**



Find a F2F HIC in Your State

TRANSLATE

 Select Language ▼

SHARE   



Enter Search Term GO

Search All F2F HIC websites:

Enter Search Term GO

- ▶ About F2F HICs
- ▶ Find a F2F HIC
- ▶ Data Reports: F2F HIC Assistance and Activities

<http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/>



organization may also be able to assist you in your state. Learn more at:

- ▶ Family Voices in Your State

Findings from Parents

› PTIs

- 38% of families report receiving thorough or good information
- **41% of families report that information was not provided**

› F2F HICs

- 32% thorough or good information
- **45% information not provided**

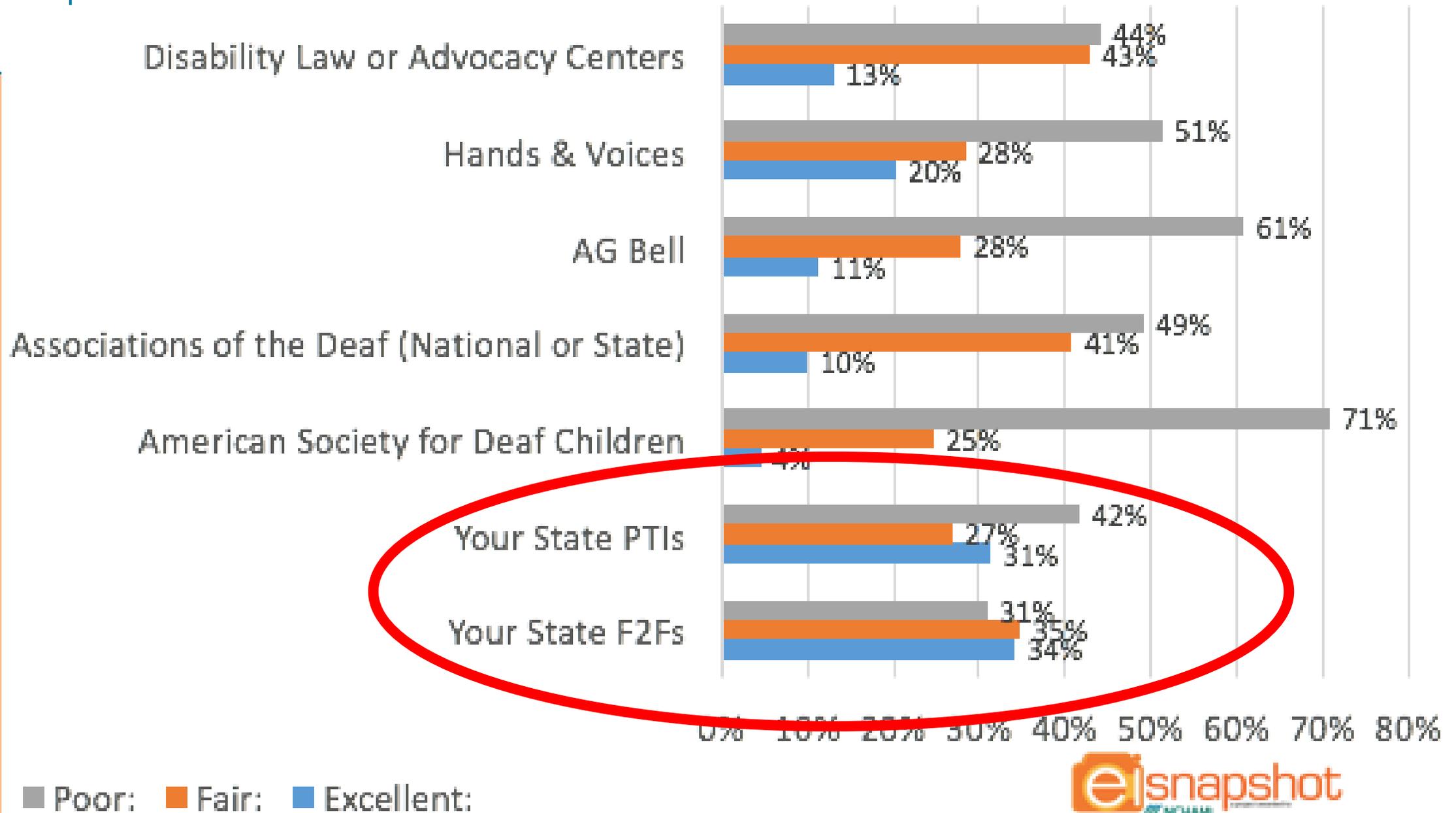
› Hands & Voices

- 56% thorough or good information
- 29% information not provided

**Preliminary Results - ongoing data collection in progress*

Findings from EI Service Providers

**Preliminary Results - ongoing data collection in progress*



Methods

- › Recruited parent consultants through the NCHAM family advisory council and parents who have attended EHDI meetings.
- › Developed, piloted and revised scenarios for script.
- › Provided training to parent consultants including a recording of a phone call to a PTI.
- › Provided ongoing training and support to families.

[Interviewer Instructions:

For each of the scenarios, please check each of the resources or types of assistance that are offered. If a link or hard paper resource is offered, please put the link or the name of the resource in the notes box along with any specific notes that you think are important. There is no need to repeat information from the yes/no questions in the notes box.]

1. *I just found out that my two-week old infant has a hearing loss. We found out through the newborn hearing screening. How can you help me?*

- Refer to early intervention/Part C (may have a specific name in the state)
 - Specific EI for D/HH
- Refer to audiology (unspecific)
 - Mention pediatric audiology
 - Provided list of pediatric audiologists
- Refer to EHDI
- Refer to pediatrician
- Refer to other organization(s): _____
- Connection to other parents
 - Specific support groups
 - Direct to specific families
- Shared or will send resources on early intervention
- Shared or will send resources specific to hearing loss

Preliminary Results

- › Very few families of children who are DHH contact PTIs and F2Fs each year
 - That is expected due to the low incidence of DHH

**Preliminary Results - ongoing data collection in progress*

Preliminary Results

- › 100% of the organizations either provided direct opportunities to connect to families or referred to another organization that provides opportunities for families to meet.
 - 52% provided direct connections to families.
 - 69% referred to other organizations
 - › Schools for the Deaf
 - › Hands and Voices and Guide By Your Side
 - › Parent to Parent programs
 - › Facebook and other social media

**Preliminary Results - ongoing data collection in progress*

Preliminary Results

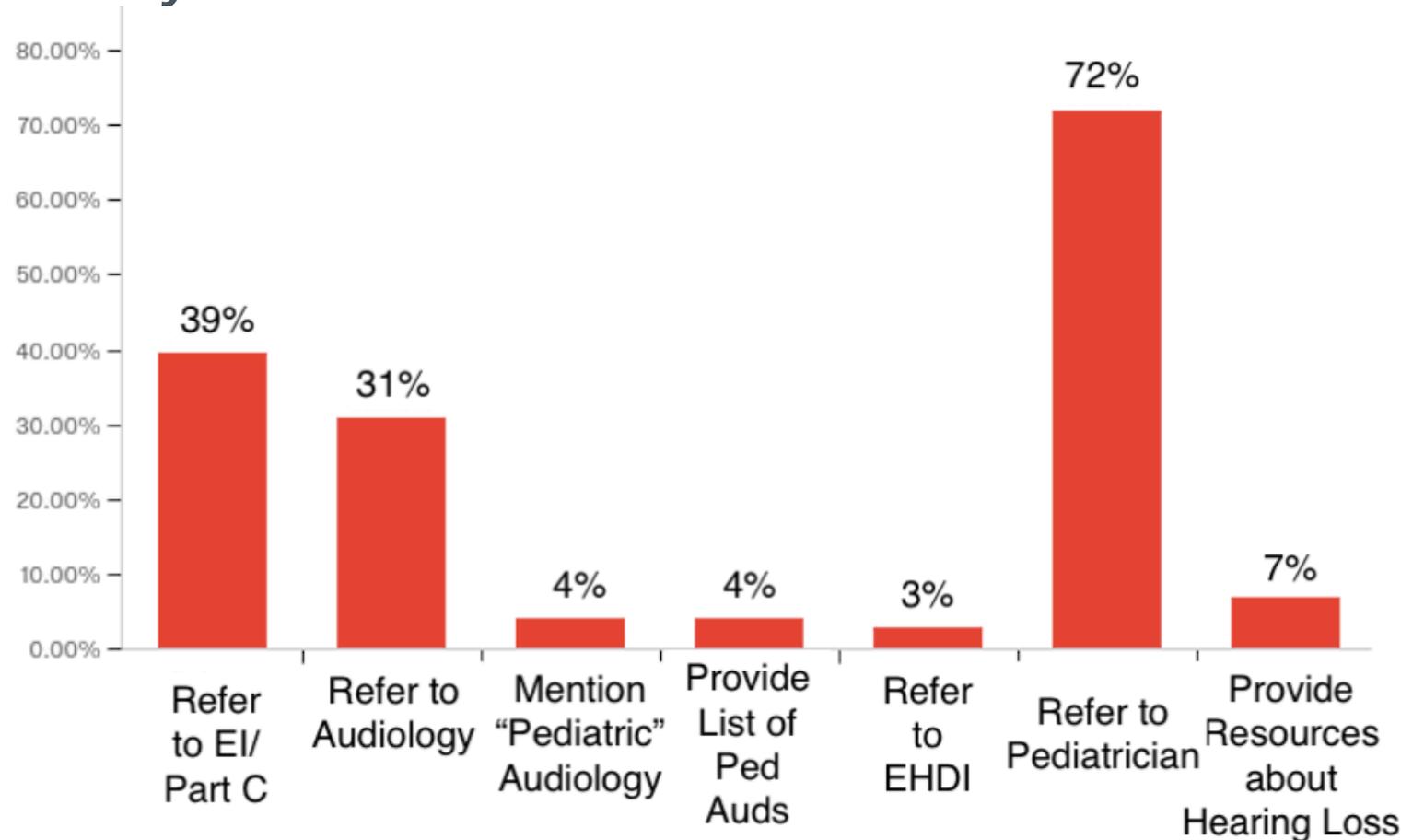
- › Scenario: My baby failed his newborn hearing screening and is now two months old but my pediatrician said not to worry about it. What would you recommend?
 - **7%** referred the parent to the **state's EHDI program**
 - **44%** referred the parent to the **Part C early intervention program**
 - **25%** recommended the parent **contact an audiologist – 0% pediatric**

**Preliminary Results - ongoing data collection in progress*



Preliminary Results

- › Scenario: I am worried that my 6-month old baby girl cannot hear me, I'm wondering if she has a hearing loss, do you know how I can find out?



Preliminary Results

- › *Scenario: My son is two years old I am hearing a lot about ASL vs. LSL and people are very passionate about both. Can you explain a bit about the different options and tell me more about potential benefits and disadvantages of each?*
 - 24% referred to early intervention
 - **4% referred to EHDI**
 - 34% offered connection to other parents
 - **51% gave unbiased advice (as judged by parent)**
 - **13% gave biased advice**
 - › All but 1 biased to ASL/manual
 - › 1 biased to LSL/cochlear implants

**Preliminary Results - ongoing data collection in progress*

Conclusions

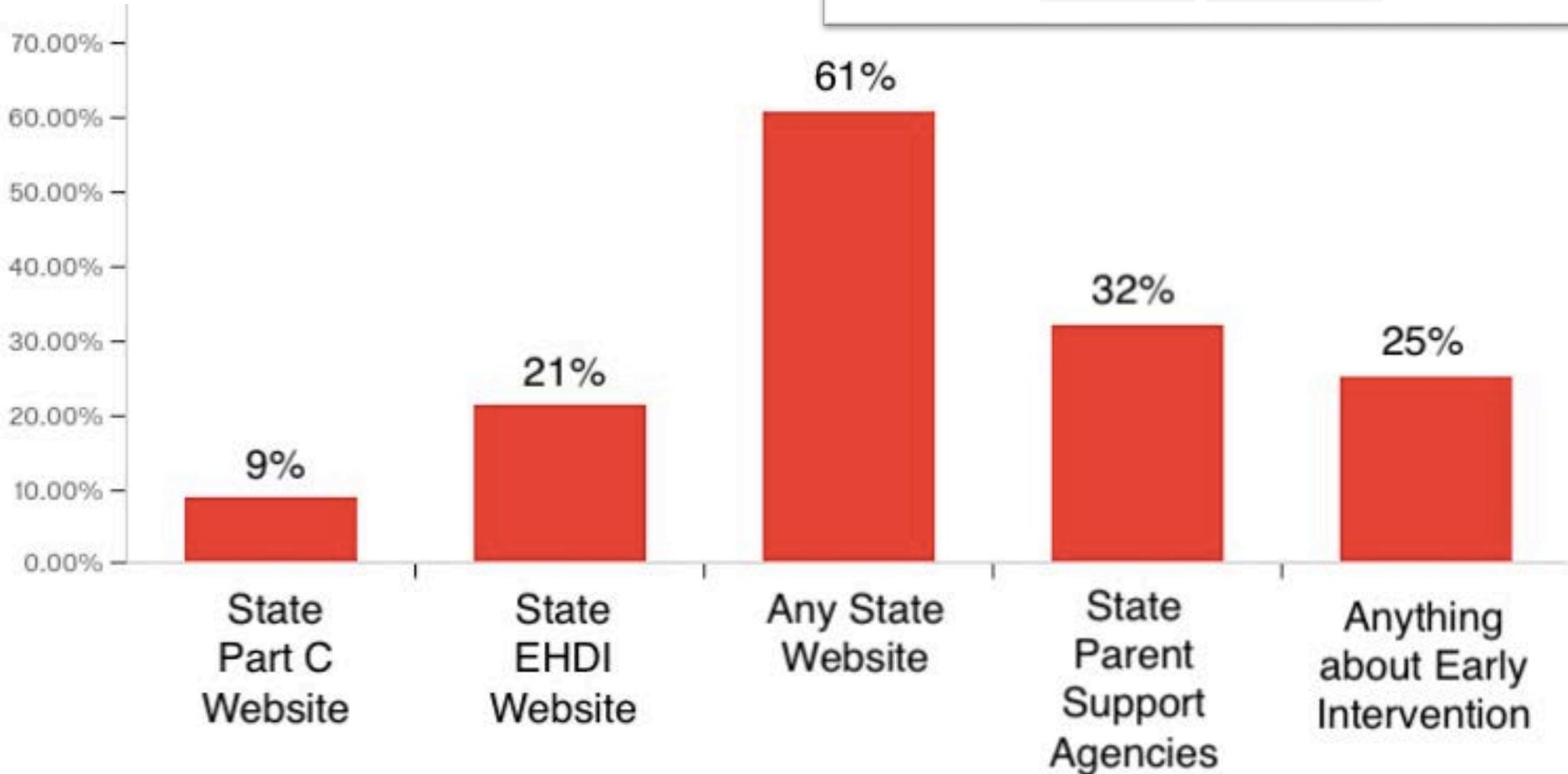
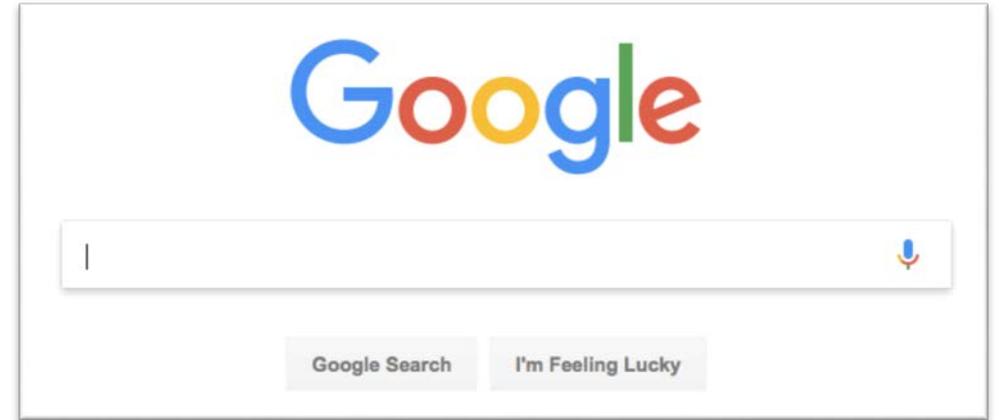
- › There are opportunities for improvement
 - Connecting **families and providers** to the resources available from PTIs and F2F HICs.
 - Teaching PTIs and F2F HICs about EHDI and about hearing loss.

- › There are great resources out there
 - No need to reinvent the wheel about the general IEP/IFSP process.
 - Connection to F2F HICs on integrated health care and other health care issues.

**Preliminary Results - ongoing data collection in progress*

**Preliminary Results - ongoing data collection in progress*

Search: [State] I'm concerned about my child's hearing



SO WHAT?

Next Steps

- › Dig deeper into these data and the connections to the data from the other pieces of EI SNAPSHOT.
- › Publish the results.
- › Work at NCHAM to develop resources to address the identified gaps.

More about EI SNAPSHOT at EHDI

- › How many clicks? Review of State Part C websites.
 - Right now, stick around!
- › Part C and EHDI Collaboration at the Administrator Level
 - 3:00 pm, Hanover F