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AMERICAN COCHLEAR IMPLANT ALLIANCE

Supporting Parental Learning and Decision-Making with Web-Based Resources: How are we doing?



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Speakers

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Agenda

- Why a review
- Overview of requirements/recommendations
- Overview of method and findings
- The parent perspective
- Conclusions

Learning Outcomes

- After attending this presentation, attendees will be able to:
 - Review a state’s EHDI Website and its potential to support a family’s early journey after learning that their child is deaf or hard of hearing
 - Identify opportunities to improve the information provided to families via the state EHDI Website
 - Explore the ways other states have addressed information provision and parent interactions via the Internet

Why a Review?

- Internet is common tool for researching health questions
 - 72% of mothers utilize the web for medical information*
 - 61% of parents use gov websites*
 - 94% of people utilize social media for medical information**
- EHDI programs/websites are top referral for parents by audiologists diagnosis infant with hearing loss

*Pew Research, 2002

**Houston T, 2021

What about families with hearing loss?

- For parents with children with hearing loss, 44% utilize hearing specific websites
- Half of parents with newly diagnoses children desired more information
- Many went searching on web for additional information on communication and other options as soon as received diagnosis
- In theory, EHDI websites should be top place

Requirements & Recommendations

7. Develop, maintain, and promote a **website** or webpage for the state/territory that is user friendly with accessible, culturally appropriate information for families and professionals that is 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 communication modalities, as appropriate.
8. Plan for project sustainability after the period of federal funding ends. HRSA expects recipients to sustain key elements of their projects, e.g., strategies for maintaining the **website** or services and interventions that have been effective in

Methods

- Reviewed 51 websites between Aug –Sept 2021
- Rated whether essential need-to-know data was provided clearly, comprehensively, and in a balanced manner on four general topics:
 - hearing loss basics
 - technology
 - communication options
 - resources for family support

Methods: Ratings

- Ratings were:
 - comprehensive
 - somewhat helpful
 - inadequate
- Based on if the information provided was thorough, unbiased, and answered basic questions change of to for of parents
- Four websites were not functioning at time of review
- Also provided are details or lack thereof that informed the decision for each rating.

Results: Hearing Loss

- Most EHDI websites provided information on hearing loss basics and/or details on 1-3-6
- Majority were rated comprehensive and somewhat helpful on this topic
- Comprehensive sites included
 - unilateral or bilateral,
 - range of loss (mild, moderate, severe, profound)
 - what can cause progressive hearing loss (such as a diagnosis of congenital Cytomegalovirus (cCMV)).
- Three States had thorough introductory videos

Results: Technology

- Ten were rated comprehensive
- They mentioned the importance of properly fitted technology and/or listed the options of hearing aids and cochlear implants.
- There was a single inclusion of the importance of an FM system
- Also included links to hearing aid financing resources

Results: Communication Options

- Content ranged from containing no information to stating that any information on options should be unbiased.
- The comprehensive sites discussed all available options.
- Most information was found in linked to parent resource guides

Results: Resources

- 37 were comprehensive or somewhat helpful
- Evaluated whether the websites included:
 - information from state and federal sources
 - resources from nonprofit organizations such as Hands & Voices, AG Bell, and local community organizations;
 - schools for deaf or hard of hearing children; information on locating medical support teams; and other resource that support a family's journey.

Results: Resources

- Location location! Also considered was ease of locating such information
 - Four sites had well rounded resources though the information was difficult to locate on the webpage resulting in an “somewhat helpful” rating
- Webpages that included link to a thorough parent resource were rated more highly, especially if the resource was easy to locate

Parent Panel

- When asked about experiences after diagnosis:
 - None could recall being referred to an EHDI website
 - Internet resources were “overwhelming” and difficult to follow because they didn’t understand the terminology
 - Every parent mentioned other parents were their most helpful resources (e.g., Facebook groups)
 - Difficulty in relating to how things sound to their child (hard to conceptualize “speech sounds”)
 - Some expressed feeling alone in figuring things out
 - Not certain what was meant by “early intervention”

The term “Parents” is inclusive of all caregivers and family constructs

Parent Perspective Takeaways

- Conflict: Needing and receiving factual information during an emotional and vulnerable time
- Hard to sort through the jargon or understand how the information applies to *their* child
- Unclear or insecure about next steps
- Various interpretations of what ‘early intervention’ means or why it is important
- Need for parent-to-parent connections
 - Turning to Facebook groups or other blogs
 - Could guidance for connections be included on website?

Jackie Hendricksen –

Parent of child who is D/HH and Consultant at Utah Parent Center



Considerations for EHDI Websites

- Ensure technical information is accompanied by interpretational support
- Minimal jargon
- Parent-to-parent connections
- Parent videos describing their journey, offering reassurance and support
- National and state resources with guidance as to *why* those resources may be needed or how utilized

The Most Important EHDI Consumer

Review the information on your state EHDI website through the eyes of your most important consumers -

Parents!

. . . and remember that your website content pertains to the most important little person in their life!

Conclusion:

Review highlights the need for more attention and resources into to seeing websites as key element of information for parents of newly diagnosed children to find medically supported, unbiased information on hearing loss and next steps.



Supporting EHDI Website Improvements

Issue	Possible Solution
Difficulties fulfilling mandates with limited funds	New funds allocated from HRSA for website improvement
Conflicting state government priorities on website focus	HRSA staff member focused on providing web support
Developing content	HRSA develop content on key topics. Highly rated websites can serve as a guide

