EHDI website review: Where Are We Now and Where Do We Go?

Nichole Westin.

>> NICHOLE WESTIN: I don't have a watch, so I think it's around 10:10 so I will go ahead and get started. All right. So I'm Nichole Westin. I'm the government affairs manager at the American Cochlear Implant Alliance and we're going to be talking about EHDI websites and review. We did with a focus on parental learning and decision-making. This is our agenda. These were the learning outcomes we posted about. But let's get into the meat of it. So back in 2021, we decided we were looking at a website for a particular question, and then it kind of morphed into doing a review of the EHDI website programs from the perspective of what a parent would need for resources. As many of you of course knows the Internet is resource for questions and this certainly came to light during the pandemic. But even back in 2022, 72% of mothers were utilizing the web for medical information and in 2021, 61% of parents were using government medical websites for information. And 94% of people utilized social media for medical information, which can sometimes be a very scary number. And other studies have talked about EHDI programs and websites are the top referral for parents by audiologists who are dying the infants with hearing loss. And our review was published in JEDI in November 22. And we watched at research hipped families with children of deaf and hard-of-hearing are looking at and parents with newly diagnosed people, 44% tried to search and utilize hearing specific websites. Half of the parents were newly diagnosed children desired more information which is often a booklet and they wanted more information and a lot of that was searching the web for information on communication and technology options as they received the diagnosis.

And we based a lot of it on the requirements and recommendations that are out there, the person before talked about the HRSA NOFO. We also looked at the 2017 EHDI reauthorization, which does require information be provided on websites to include unbiased information on hearing technology and we also referenced the NCHAM resource which includes suggestions for websites. And there were actually some updates in the most recent reauthorization of EHDI in 2022. The reauthorization language contains geo report language addressing certain populations and also looking at how parents are receiving the information which includes EHDI websites. It also maintains the 2017 unbiased tech requirement. And there was also another bill that included language on EHDI, which was the giant Omni bus appropriations bill of 2023 which funded the entire government for this fiscal year. And there was language that encourages HRSA to work with partners to advance awareness about the wide range of modalities of hearing technologies and other information available for children who are deaf and hard-of-hearing.

So looking back in 2021, when we did our website review, we looked at the 50 websites which were the 50 states in the District of Columbia between August and September of that year. The goal was of course to be objective. We did not review the social media presence of the EHDI programs, because that's just a lot. And the four areas that we looked at in particular were hearing loss, basics, technology, communication options, and the resources for family support that's provided. We rated things in the categories of comprehensive, somewhat helpful information, and inadequate. And it was generally based if the information provided was thorough, up biased and answered basic questions for parents and at the time, there were four websites that were not functioning when we looked at them in 2021.

So this was the criteria we used for the hearing loss. For comprehensive, we were hoping to find information on the types of hearing loss, possible causes of progressive hearing loss such as CCMV and what a family might expect during an exam. And at the time there, were 3 websites which had introductory videos which encompassed all of this information, including technology, communications, what to expect and what it was like having a child who was deaf and hard-of-hearing and the EHDI process.

For somewhat helpful sites, those sites usually had kind of the introductory information on hearing loss. And a lot of them might just have what the EHDI, the 1-3-6 guidelines and there were sites that didn't have any of that information. And those were rated inadequate. And this was the breakdown of the 51 states. This was actually the category that had the most comprehensive at 39%. And it also had the least inadequate. The communication criteria that we used is if they had unbiased information on all the optionals, ASL, spoken, cued speech, total communication, et cetera. Other details on where to find such information, such as if you're looking at this, this is where you can go if you're thinking about this, we recommend, you know, here's a website for Hands & Voices. And things long those lines. And we did include for comprehensive, if it was just a link to a comprehensive parent guide with the information on communication, that was included as comprehensive. It didn't have to be on the website that linked to a PDF file, and that counted. One might list an option in the sentence that was rated somewhat helpful, because at least you knew what they were. And site AWS named inadequate if there was no mention of communication option or if there was a clear bias. And this is how this broke down of the 51. And then for technology, kind of similar to communications. If it had information on cochlear implants, hearing aids, and any additional technology options, is couple of sites p included name on FM system and how to utilize those in a home setting or education setting, daycare, et cetera.

Tips on using the technology and/or non-insurance financing options. And that was generally focused on hearing aids. To be somewhat helpful, at least one option needed to be mentioned. And more often than not, that was just hearing aids, including information on when to get them. And a site was rated inadequate if there were no technology options mentioned at all. And that's how that broke down. So this was the one where comprehensive was the smallest and inadequate, because there was no information about technology. For resource criteria, and, again, we were trying to look at it from the perspective of a parent versus the provider. We looked at whether it included information on state or federal resources, CDC, local Department of Health and education, the NIH, et cetera. Certainly it was going to be a higher rate field goal it had information on Hands & Voices, AG Bell, and the like. Also if they had information on the state schools for the Deaf, private oral schools and public schools with special programs for children who were deaf and hard-of-hearing, because often you might have a parent who's like, well, now what are they going to do when they're older and they're going to go into the school system, so having that information was incredibly helpful. Ratings were lower if they listed resources focused on one option with no mention of others. Honestly, if it was hard to locate or outdated, it was going to be rated lower. I mean couple of sites you had to keep digging, digging, and digging and clicking links before you can get to the resource and parents might give up at that point and that's how this broke down. So comprehensive was just a bit lower than under the hearing resources.

So then coming out to 2023, of course, you know, we realized as we were looking at this and writing it up that a lot was going to change over the 18 months because of the world completely changed due to COVID and having conversations with people that they were working on updating thing and things have gotten ham strung. So we decided to go back. We also initially just wanted to kind of look at those four sites that weren't working in 2021. And of those four sites, one was now comprehensive across all four categories. One was improved in a few areas but lacking information on communication and resources. And two were functioning, but were still kind of inadequate across-the-board. And then from there, we decided to kind of do a random selection from those 51 areas and we just looked at total of 20 sites to kind of give us a broader view of what was happening without having to do a full complete redo. And we did kind of choose from comprehensive. The ones that were comprehensive across-the-board. The ones that were inadequate across-the-board and bunch in the middle to see if things had changinged. And we used the same criteria we had before that I gone over for hearing. It was a redo with the fresh look at those websites and more importantly, we were looking to see once we compared it to the previous stuff, if anything had changed either up or down.

And I was thrilled that no sites were downgraded in any of the categories. And more states were comprehensive overall than in 2021. So there was that change between that and 2023. The comprehensive sites, all stayed comprehensive which goes to show if you have a really well built website, you can update a few things, but once the structure is really functioning really well, it's easier to maintain than starting over but a lot of did start over. Some were helpful in the middle. When I looked at them, yeah, I've seen this before. So it was kind of, they haven't done anything since 2021, and obviously, there's going to be reasons for that. Or they improved in couple of different areas. And what was also exciting is that number of sites inadequate did improve. And I was looking at the data and I was excited animating graphs. This was a big day for me.

So starting with comprehensive, we're going to start, the blue is of course 2021. So 5 states were, of those 5 states that we looked at in 2021, 5 were comprehensive. 7 were somewhat helpful and 8 were inadequate. So for 2023, it was a huge jump incomprehensive. Somewhat helpful. It was a drop-off and that's what we want to see. And for inadequate, it was a huge drop-off, because a lot of sites bumped up the comprehensive. So for the next category, communication, again, looking back for 2021, 6 comprehensive, two somewhat helpful, 12 inadequate.

And then for 2023, it wasn't quite a huge or big of a jump, but still 4 sites made the inclusion. And then additional ones went from inadequate to somewhat helpful. And then this was the drop of inadequate, which of course, we're happy to see. And then kind of the sale thing for technology. This is where we were before. And this is where we are now. And we're seeing the growth when we want to see it and which is great.

And then the final category resources. This is where we were. And of the 21, this is where we are now. So when I did this, when we did a virtual last year, we really talked about the parent perspective about, like, what they're looking for in websites. But I thought it was only fair to go to some of the EHDI personnel this time to talk to them about, you know, what were hindrances when you were facing, updating, and maintaining the website. With the content and input and reats and what made your job easier when focused on a website and we reached out to a number of them. We heard back from some. They said, hey, EHDI conference is coming up and we may not get back to you right away. From those we heard back, it was absolute no surprise for lack of hindrance is funding and staffs who are able to focus on this because of pressure from other areas that they're working on, of course. A few mentioned that the state guidelines for websites, if it's awebsite located on the general website, those are changing and hindering updates, that could change with administration change and staff change and higher up and you're always juggling that process. Some states require that updates on the state website has to go through the state of office communication to improve the website. You can do all the work and they can come back and say we don't like any of this even though it's required of the other stuff and that could be a complication. And of course, impact of COVID. All of the above. I was told by couple of people diverted to updating what was going on with COVID. It was more important to make sure people knew how to access the telehealth, et cetera. And of course, conflicting priorities. They might just have not enough staff to focus on this and they're more focused on meeting some of their other mandates.

Excuse me. [Coughing]

Developing content. A lot of them looked at other EHDI websites. Or the state programs to kind of pull the content from. [Coughing] excuse me. [Coughing] I know there's work with EHDI advisory boards. For the parent and professional input, -- excuse me. Many did include parent input by established task force. Others did contract out for website development out for ease of use and updating by EHDI staff. And again, the EHDI Advisory Board played a key role here when it came to input from other professionals and parents. The person who spoke before, a lot of them could partner up with a lot of groups such as Hands & Voices and others to kind of develop the content and share the cost. When it came back to making the question about making the job easier, I had one person, just said I have no idea what would make my job easier when developing website content. One replied, standardized content that's available, whether it's from HRSA or NCHAM or the like that we can easily pull from. Another person indicated that standardized content is helpful, because it gives you a starting point, but then they're able to take that standardized content and massage it to meet the needs of their state, and then unique needs of their state whether it's rural or urban areas. And of course, financial assistance, as for the developing of the content, developing of the website, and also somebody pointed out that the state program itself can often bare the cost of translating the website ensuring they're accessible. And so additional funds to offset that can be helpful as well. Or like the person before, is able to use the platform and double-check the information. This is something I would love to hear from people in the room that would make the job easier maybe going forward.

And these were some of the things that we talked about in 2021 that honestly, still holds true in 2023 about ways, you know, the broader community can help support EHDI website improvements. If you had the issue of difficulty fulfilling all the mandates due to limited funds, it would be nice if HRSA is able to allocate funds for website improvement. Because it's part of NOFO, whether it's through grants and the like. And new funds, not just taking away from the funds that you all are allotted for website development, but additional funds on top of that. Conflicting priorities. If HRSA is able to have a staff member or other people such as NCHAM or other groups, people who are focused on providing website support, people that you can reach out to say, you know, is there a better platform? Anything along those lines just to have a person that you can bounce those ideas off of to kind of standardize everything a little bit.

Then the big one is developing content. You know, whether, again, HRSA or other people can help divide those. The highly rated websites also can serve as a guide, especially those that win NCHAM award every year. And to reiterate, when we were doing the guide and review, if the websites had links to different resources in paper, those counted for us. They may not be a super-pretty website, but as long as information is there and clear and you can click on it, that's going to give the website a comprehensive review, because that was what we were looking for. What is the parent going to click on and read and find it very helpful? So there still needs to be attention-focused on this area. But situation has certainly improved within the 18 months and I'm certainly hopeful this will continue into the future. So does anybody have any questions?

>> [Away from mic]

>> NICHOLE WESTIN: That was my recommendation, not a HRSA. Actually we have. They're like, you know, it's certainly something we can share again in the future. I think the question has to be mic'd. So we'll give her a second.

>> On the issue of HRSA allocating funds for this, you all could suggest that they do that, that you need this kind of help, you know? And when we started this project, you know, we did it because we had gone through ourselves a major website redesign. So I know how hard it was and we had a consultant to help us. We got a package, the prior presentation talked about how expensive it was. I don't think it's that expensive. You know, the numbers that were given. I think you can do it for a lot less. And you can also buy a package that allows someone with just a little bit of training on your staff to do the updates and that's how we do it. We don't have someone pay someone $250 a month to update the site.

So I think those were the drivers when we looked at this. But I think it would be possible for HRSA to have someone that's a resource to you all that has, you know, the ability to advise. You should suggest that. I mean, we're not an EHDI coordinator. So we don't really have the ability to say that, but you do. You know, and it would be a way to help you move this forward and get past that initial difficulty of improving the site to the point where you can maintain it yourself and add this kind of content to it.

>> This is Gina speaking. I'm the EHDI coordinator for Michigan. We are one the sites that is redeveloping. And I'm trying to understand. So you're from American Cochlear Implant Alliance. And we're one of the sites that was inadequate for technology. We're looking to make improvements, as an audiologist tasked with understanding websites now. Do you foresee any type of support from ACIA for the technology part?

>> NICHOLE WESTIN: We have information on our website. One of the things we did include for comprehensive, I did talk about it a little bit. If you listed information for CI, that's linked to us. Hearing aids, people were linking to very companies or HLAA does a lot of hearing information as well. So we're also, if you just want basic information on C.I., we're happy to provide links to that as well.

>> Yeah, I would love pictures or, you know, one thing the previous presenter talked about was representing all types of communication. And we're finding ourselves struggle to go find naicts are appropriate and multicultural.

>> NICHOLE WESTIN: Absolutely. We've got kids who use C.I. and everything across-the-board, so we're happy to share that information and I've got my business card that I can hand it to you.

>> That's wonderful. Thank you.

>> Two things, are we able to get copies of the slides so we can look at the factors you were looking at rating the website? Where do we see where our state fell into?

>> NICHOLE WESTIN: Full thing was published in 2020 and the publication is on our website. On our website and also in JEDI. Umm-hmm.

>> [Away from mic]

>> NICHOLE WESTIN: I'm trying to remember where it is on our site. I think it's under early intervention. If not there, then I can send you a copy of it because I had to share it with my parents. [Laughter] But I've got my card and I'll provide it to people.

>> If you have notes, do you all have notes on the specific state websites? Are you willing to share them no matter what category they fell into with the specific state EHDI site? As means of improving it?

>> NICHOLE WESTIN: I'm happy to talk to people about it. I just have to figure out where the full notes are.

>> Hi, I'm Shelby representing South Dakota. We don't have a EHDI coordinator but I'm a HRSA project director and I wondered, we are a state where our EHDI site is separate from our state site but it's never been acknowledged. How did you know in states like that? I think past one where it's not the stately website?

>> NICHOLE WESTIN: So when we were looking for the websites, we kind of started with the NCHAM list of websites, but a lot of those links are broken and I would just Google infant newborn screening, EHDI programs and things along those lines. If no sites appeared no matter how many times I searched for it, that's why we ended up with the four that were kind of inadequate. One said that, you know, updating in progress or something along those lines. If we clicked for the link and we looked to see if we can find other stuff.

>> I don't know if it was included or contacted, we have a lot of confusion. Our state is not normal so, I like to know what you found out.

>> Do you all plan to publish what you found for 2023? Like the comparison?

>> NICHOLE WESTIN: I know we were going and we talked to JEDI do an aaddendum for the states that were not working and we talked about that. But I don't know if we're going -- I don't know if Don and I talked about doing that. If we were going to do a study, I would almost prefer to do a review of all the sites again. Because, like, I know Illinois was not included in the 20I talked about and I know they did an update. If we were going to do another review and have it published, I personally prefer toe do all 50 for fairness purposes than doing just this update here. I think, but I don't want to talk for Donna who also worked on this with me.

>> This is just a suggestion. I mean, the other thing listening to you all, I think discussion has come out because of the publication of this article. And I think I could envision us doing a new piece that summarizes the discussion and what else can be done? The suggestions that we came up with in the journal article really came from discussions with people like yourselves, like what would it take to help you move the needle on your website and one thing we didn't talk about, either in Nichole's presentation or the one prior is, but you alluded to it for South Dakota and finding your site. It's something we call search engine optimization. So if the parent goes on the web and looks for a site, whether or not they look, you know, through the national EHDI information where they find it, and that's really important for you all to do with your sites. You know, and I can tell you when we started revising our site, I never heard of that term before. But it's something that we spend a lot of time on now. So if you Google certain terms related to cochlear implants, you end up on our website. And that is something you should pay attention to. You know, so that people searching for it will find your site. So I can see us doing another article that basically pulls from the experience that we've heard after we published this. Really, all we were trying to do is have people pay attention and it's really had that effect. Because first thing you want to do is go on and see how your state has done and get better.

>> NICHOLE WESTIN: Yeah, I got a lot of emails. To your point, it's good idea to go back and did it. But we originally did it from a parent perspective. Like what a parent would look for. But also taking into consideration what the EHDI coordinators face, because we can come out and say this is a great idea. And you can all laugh at us. So kind of trying to structure it just a little bit differently might be a good idea. Because I do know that I did hear from some people who were like, well, ours was not rated great because COVID derailed everything and we're going to update it later. Which is why we looked at those 20 sites because I knee people were updating it. And I'm very cognizant of that. This is just a snapshot of what we see on any given day and we just happen to look at it. And I might look at a site and think, this needs room for improvement, so I put somewhat helpful. But 3 days later, the person goes on and completely update the information and I don't know that. So it's good to talk about it as an ongoing process. I don't know what time it is. I'm sorry.

>> There's about a minute left. I'm not sure if there's enough time for another question. But we can give it a go.

>> NICHOLE WESTIN: If I can't answer up here, I can answer it afterwards.

>> Hi, I'm Vanessa from Minnesota. And actually my question might be more directed to you as in how do you get your website to be the first thing people pull up when a parent goes on and the optimization?

>> It really has to do with what you put on your site. It has to do with the content on your site. And you have to use good clear words that people are going to search for.

>> [Away from mic]

>> Well, to put the content on your site, no. Yes, we pay. And we have a consultant who's job it is in the world to help people make their websites work better. So that's another thing that if this group were to try to get HRSA to help you, that you could ask for. You know, that would make sense, because they could have one firm whose job it would be to help EHDI websites get noticed on the web. So that you wouldn't have to try to do that. It can be expensive. I'll be honest with you. It can be expensive. It's probably beyond your budget. But you still can do without hiring a consultant. You can still be careful about the content you put on your site so that when somebody Google's, they end up on your site. And it's easy to test it. You put the content up, then you Google and you see where people end up. So there are things you can do without hiring a consultant. And I recommend that you do it. And we put more money in it than you can, but you can still improve it.

(Applauds)