NCHAM-Readability and Usability of EHDI Newborn Hearing Screening Brochures.
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(Please stand by. The presentation will begin shortly)

>> SAMUEL ATCHERSON: Okay, Nan asked me to go ahead and take her place for now. Until she can get her microphone going. I don't want to delay everybody else. Is that okay?

>> That sounds perfect.

>> SAMUEL ATCHERSON: Okay, great. Well, anyway, apologize for the technical difficulties, but here's the topic that we're really excited about. Something that we started doing about two years ago and has since been presented twice at the EHDI conference recently and then one a year ago.

And so without further ado, let's just go ahead and begin.

This is a slide that Nan created. Addressing diversity and health literacy. And we've got a number of slides later to let you know who that risk for what we would call low-health literacy.

But we would want to preface that with some information about what health literacy actually is.

But as you can see from this slide, there's a number of different terms that might come to mind when you're thinking about diversity and health literacy. So if you'll just scan that, I'll just mention some of these words. Patient education, early identification, health

outcomes, healthcare costs, diverse population, cultural competence, so on and so forth.

There's a lot that we need to think about. And a lot that we need to wrap our heads around. But health literacy as a concept in and of itself does not have to be difficult, but it just means that there's a way to bridge the gap between patients, families, clients with their health providers.

Here's a map showing the diversity. Nan would have to help me with this trying to understand exactly what this slide is showing. So until Nan gets here we will address this later.

So here is health literacy defined. And there's a number of different definitions out there and as you might imagine, there is certainly controversy about what's a good definition, what's a bad definition, what is restrictive, what is too broad.

But here's a couple that we like. The U.S. department of health and human services would define health literacy as the degree to which individuals have the capacity to obtain, process, understand basic health information and services needed to make appropriate health decisions.

And so you should see three words there. Obtain, process and understand.

That's simply not enough to just hand a family a brochure for example.

We want to make sure that they can process that information, understand that information in order to be able to make appropriate health decisions.

The next definition there by the Institute of Medicine would define health literacy as a shared function between patients and the way they interact to obtain and understand health information. So here we're talking about the interaction between the patients, parent or family and anyone with whom they interact.

So this comes out of a national survey conducted on the U.S. population in terms of where will they stand in terms of their health literacy abilities.

They divided health literacy skills into four separate levels as we can see here. There's the low, basic, which is for example no more than the most simple and concrete literacy skills.

And by the way, when we think about health literacy, that's a little separate from functional literacy. Functional literacy would be what you do in the classroom. What you engage in everyday conversations.

But here we're talking about health literacy. So we've got 11-15% of the entire U.S.

population that falls under that below basic.

This is the group that's really at risk. And then we've got basic skills necessary to perform simple and everyday literacy activities.

17-23% of the U.S. population.

And then we get a little bit more advanced into immediate skills necessary to perform moderately challenging literacy activities. About 50% of the population falls there.

And finally we've got proficient. Skills necessary to perform more complex and challenging literacy activities. Again, that drops down.

Ideally, it would be nice if the U.S. population fell within intermediate and proficient. But the fact remains that we've got about 30-40% who are really at risk.

So what is the health literacy evidence. What do we know from the literature about where we stand in terms of health literacy? Populations at risk include those with low educational attainment, elderly, minority population and immigrants.

Only 22% of adults. One out of five in America have basic health literacy skills reading at or below the 5th grade level.

There's some other stuff out there related to reading grade level.

As you see down here, the average American reads at the 8th grade level. So that's what I was referring to earlier as functional literacy. But when we're talking about health materials, 5th grade, that's about 2-3 grades poorer than functional literacy.

Another 14% of adults, one out of ten in America have below basic health literacy skills. And there's evidence that most health related materials are written at the 10-grade level or above.

College, Nan and I certainly have studied the readability of various materials in communication disorders, and we have found some things to be written at the college or graduate level.

So I'm just going to go through a series of slides very quickly just to have you wrap your head around this whole concept of health literacy and just how problematic it can be.

But the good news is that we can change some of this stuff. We can effect change and we can make this a better place.

But to start with, the most recent statistic that we've seen is that there is an estimated annual cost to U.S. healthcare system of $100 + billion. That is a huge number to

consider.

And imagine just how much money is wasted because of issues related to health literacy.

So who's at risk? High school dropouts. Criminals. Individuals 65 or older. Latinos or Hispanics.

And what I may add to that, they have surveyed African Americans, Caucasians, Asians and Hispanic, and what they have found is that generally all other groups have generally low health literacy, Hispanics fair worse off compared to the other racial or ethnic groups.

African Americans, American Indians.

Those who did not speak English as a child, but might have learned later.

Any recent immigrant who does not speak English. Anyone who is sick or disabled.

And you may be very well educated, but when you are sick you are not making good decisions potentially.

And in terms of disabled, that can refer to anyone who might have hearing impairments, speech/language impairments, cognitive impairments, so on and so forth.

Anyone on Medicaid or Medicare is at risk. And though I have thrown out a number of individuals at risk for low health literacy, let's not forget that Caucasian native born Americans. Remember, we had this statistic where across the United States most Americans on average are reading at about the 8th grade level.

Now certainly our melting pot is changing. In just a matter of years, decades, we will see more minorities than there will be Caucasians, but for the time being, just because you are Caucasian does not mean you are not at risk for low health literacy. So here's why. Here's some information.

People with college degrees who have below basic literacy skills. 3% of the population. 3% of people with college degrees have low or below basic literacy skills.

Just to drive that home, one of our colleagues has a college degree, a masters degree, and a Ph.D. He is a speech pathologist. A couple of years ago he turned 50. And one of the things that comes with turning 50 is to have a test that extremely uncomfortable. A urology exam. He made an appointment and he received some information in the mail. He read through it and he thought he understood what was in that. He handed it to his wife and his wife read it. And by the way his wife has a master's degree in speech pathology, and she came away with a different conclusion about the materials that he

was given.

Because there was a disagreement about who was right, a colleague called a nurse at the urology office to get some clarification. As it turned out his wife was correct.

Now here's an individual with three degrees. College, master's and Ph.D. And yet he didn't understand the information that was presented to him. Does he have low health literacy? Absolutely not.

But the materials he was provided were left up to interpretation.

Many patients with limited health literacy skills will hide this from their spouses. Most patients also hide this from their doctor.

And patients will report shame and embarrassment when it comes to the discovery that they have low health literacy. So in terms of the importance of health literacy and really getting into the meat of what this particular webinar is all about, in order to take part, patients and parents need to be able to use health information.

So again, not only obtain and process, but to actually understand. And we can break that up into even more areas. You need to be able to access it. Whether they are doing the search themselves. Perhaps getting on the internet to find information.

They need to understand it. Is it written at a language that's appropriate for the average American? Is it written at a grade level that's low enough?

Is it presented well? Is it organized well?
Communicate. The things that we say in our everyday communication. Perhaps bedside chats with patients or families.

Anything that a health professional fight possibly say.

Evaluate. This is where you've got the patient or family taking the information and evaluating what has been presented to them.

Do they have that ability?

And finally, apply. You may have recommendations. You may have treatment prescriptions.

You may want to for example recommend followup newborn hearing screening because there was a failure. Are they able to take that information and apply that?

And factors to consider for written materials. Here's where we get into the study that Nan is about to address with you. On the one hand, we were looking at the readability

of newborn hearing screening materials across the country. So in terms of readability what are we looking at? We're looking at the content. We're looking at the average word length. Longer words with multiple syllables are more challenging. What's the average sentence length? Studies have shown that shorter sentences tend to be better than longer sentences, so long as you do not disrupt the content.

And finally formatting.

So all of those things will matter in terms of whether the brochure is written in narrative form or bulleted form. Are there pictures? When you look at user friendliness, this is something that is newer in our field. Not only can we look at readability, but just how user friendly are the materials that we're presenting? Is it laid out well? Are there good, useful illustrations? Is the message clear? Are we dumping a lot of information on users and their families, or are we giving them bite-sized relevant information?

And cultural appropriateness. And a good example of that would be to make sure that the information is not biased toward any racial or ethnic group? Pictures to represent that there is diversity out there.

Okay, at this time I'm going to see if I can find Nan and allow her to take over this section. It may be that she needs to use my office and I just realized that my office door is locked. So if you'll just give me a moment.

>> NANNETTE NICHOLSON: Okay, and I'm going to go ahead and try and see if my mic is working or not. Could somebody let me know?

>> Daniel: This is Daniel. It's working.

>> NANNETTE NICHOLSON: Fabulous. Okay great.

So I'm going to talk about the study that we did about readability and usability of EHDI brochures. And one thing that I wanted to bring up was a study that ASHA did in 2008 that was actually on lost-to-followup.
And they identified some family factors and some child factors that contributed to lost-to-followup.

And one of those things was literacy. Now none of the studies that they reviewed or rated in their systematic review addressed health literacy specifically. But it was a risk factor that contributed to lost-to-followup.

Okay, so we know that there is a mismatch between reading levels of health information materials and the reading level of the intended audience. In a recent study of parents' literacy, this was done by Yin in 2008. He studied a sample of 6,000 parents to see how they could perform in terms of basic or below-basic health literacy.

64% of the parents in this population were unable to enter names and birth dates correctly on a health insurance form. 66% were unable to calculate the annual health insurance policy on the basis of family size. And 46% were unable to perform at least one-two medication-related tasks.

So it really got us to thinking about parental health literacy and whether or not some of the written health information that we have contributes to healthcare disparities.

So in 2006 they did a study on newborn hearing screening brochures. And he used 48 brochures from different states on a wide variety of screening programs. And what he found was that the average reading level of the brochures that he studied was in a range between the 10th and the 12th grade level. And he recommended that they be revised and brought down to a level of 8th grade or lower.

Arnold and colleagues also studied user-friendliness of the brochures. And had them rated on the five areas that we talked about a little bit earlier that Sam mentioned.

So what our study entailed was that we downloaded all of the available U.S. state and territory brochures on newborn hearing screening from the NCHAM website.

The text was copied electronically and pasted into a Word document and saved as an ASCII text file and then loaded into this readability software for analysis.

And I'll tell you a little bit later we have since located a couple of resources, online resources, where you can do readability checks for some of the different formulas. But using this readability software we obtained the flesh reading E-score, the forecast, the Fog index, and the simple measure of gobly gook that is known as the SMOG.

This is a table that provides the descriptions for reading ease estimates. The first one is reading ease score that uses sentence length and the number of words to get a score. And the higher the score the easier, the easier it is so read.

So a score closer to 100 is better than a score closer to 0. And this Flesch score is used to estimate the Flesch-Kinkade level, which can be done easily in MS Word.

And the Gunning Fog Index used average sentence length and the percentage of hard words to calculate a reading grade level.

The forecast uses the number of monosyllabic words. And the SMOG uses pol ysyllabic words to estimate reading grade levels.

And we wanted to look at these four grade level estimates to see how they compared to each other and also to see how they compared to Arnold's study.

So the readability for the early hearing detection and intervention brochures for 48 brochures is shown in this table. And you can see that the average reading ease score was 73. Using the Flesch-Kinkaide the average reading estimate is 5th grade level, which is fabulous. Using the forecast, it's 10th grade level. Gunning Fog, it's 8th grade level. And the SMOG is 7th grade level.

And here's some distributions in percentage. The percentage of brochures that fell into each category for the grade levels associated with them.

The interesting thing is that in the bar graph we can see how the Flesch-Kinkaide returns relatively low grade estimates where as the forecast, which is this darker color returns the highest grade level estimates. And the FOG is the most widely distributed grade level estimate and then the SMOG is kind of a mid-range estimate.

So if we can compare our study to the Arnold study, we see that the ease of reading, our average ease of reading was 73, which as I said the closer to 100, the easier it is to read.

Whereas for the other newborn hearing screening brochures, the average was 53.

And the Flesch-Kinkaide grade level estimate for the EHDI brochures was 5th grade, whereas it was much higher for the other newborn screening brochures that Arnold studied.

And then Arnold's study did not include the other grade level estimates.

So the implications for EHDI programs is basically that it really is a good idea to check out and use grade-level estimates when you are designing newborn hearing screen brochures. The Flesch-Kinkaide are easily accessible in microsoft Word.

And then the FOG readability grade level and the SMOG readability grade level, these are both rather than just reading, these are an index of understanding.

And both of these might be a more realistic indication of how well, or a prediction of how well the patient can understand. And there are online. There is online access to readability calculators for both the FOG and the SMOG. So those are readily available as well.

And then I wouldn't really recommend the forecast. I don't really think it's appropriate for our assessment of readability for our brochures.
Okay, now the other thing that we looked at was usability of the EHDI brochures. This indicates the ease of use.

So for written materials, it often includes readability, how the content is organized, the appearance of the format, the overall tone and the cultural appropriateness.

When we looked at, um, Arnold's study, his user-friendliness checklist included a lot of those categories. So we decided just to use his checklist. The 22-item checklist.

And we had 23 participants in our study. Five parents, seven allied health professionals who were audiologists and speech pathologists. We had eight students and those were audiologists and speech pathologists.

And then we had three other participants that didn't really fall into any one of these categories specifically.

So in response to the question, how much work does this brochure need to be user friendly.

Participants chose one of these three answers. It needs little work. It needs some work. Or it needs much work. And again this is exactly the same checklist that Arnold used in their study.

So items 1-5 in this 22-item checklist are aspects of the layout. Items 6-8 have to do with illustrations. 9-13 have to do with the message. 14-18 with how manageable the information is. Whether or not it's chunked appropriately.

And items 19-22 have to do with the cultural appropriateness of the content. And this shows the, the graphic shows the different aspects for each of these areas. So for layout, manageable information and clear message, there are five different aspects that are rated.

And for illustrations and for cultural appropriateness, there are three and four items for each category.

This is a table that shows the mean ratings in each of the categories by participant. So along the vertical axis we have participants. And along the horizontal axis we have the different categories.

And as you can see the scores all hover around 1.5 except in the category of illustrations. And the audiologist and speech pathologists who are intimately familiar with the content rated the illustrations not as harshly as did the other groups. It was closer to 1.5. Whereas the other groups all rated the category of illustrations as needing some or much work.

And you can see that a little bit better in this bar graph. Again, all of the ratings fell pretty close together for each of the different categories except for in illustrations. And the audiologist and speech pathologist were the ones who rated that as needing less work than did the other three groups.

This is a sample of the proportion of ratings for all participants for the group. For example, on the layout, 61% of our 23 participants rated the font as needing little work. 35% rated it as needing some work and 14% rated it as needing much work.

And you can follow these aspects on down and see the associated percentages.

With illustrations, 39%, it was more evenly distributed overall when all of our participants were averaged together.

So 39% said it needed a little bit. 33% said it needed some work. And 27% said it needed much work.

So there was a wider, it was more evenly distributed across those categories. When we compare the user friendliness that Arnold did with our brochures with the user friendliness of the newborn screening brochures, we could see that all of the items were comparable. Except for our brochures, the illustrations were graded higher or with a higher proportion, by a higher proportion of participants than the Arnold study was.

So the implications for practice are that there is a user-friendliness newborn screening brochure checklist that's a simple tool and can be used when developing EHDI brochures.

And another important thing is that it's really important to include stakeholders in this development process of EHDI brochures. Because the ratings may vary independently on the perspective of the participant. So that is something that we want to take into consideration and be mindful of. And that includes whether the brochures are done in English or Spanish or any other language as well.

So the action steps for EHDI brochure development are to use the readability checks and the Flesch-Kinkaide, Gunning FOG and SMOG as necessary to check your reading levels and also to use the user-friendliness checklist to guide brochure development.

In the brochure, explain the purpose, limit the content, involve and engage the reader. Make it easy to read. Make it look easy to read. And use visuals that clarify and motivate.

And I'm going to go ahead and turn it back over to Sam.

>> SAMUEL ATCHERSON: Thank you Nan.

So I hope that our particular study was helpful to all of you. I think it's an interesting process. We were pleasantly surprised that there were some very good EHDI brochures out there. And some that were not so good. But the ones that were not so good were not as bad as we saw reported in the Arnold study.

I think as an EHDI entity we did a very good job. We can always work toward improvement.

So our challenge to you all is that every time you are considering revising your materials, you now have two extra tools to use. One would be evaluate the readability of your materials, and two, as Nan suggested, involve stakeholders in evaluating the user-friendliness of those materials.

Also as Nan had mentioned, she talked about the forecast formula. One of the downsides of the forecast formula is that it really only takes into account single-syllable words. So the grade level for the 48 EHDI brochures was rated to be at the 10th grade level.

So I completely agree with Nan that that would probably not be an appropriate one to use. Generally speaking, our brochures are probably a little bit more narrative. And if you supplement it well with illustrations as culturally appropriate and the organization makes sense, the font is at a size large enough to read, and you're not using crazy fonts. Just stick with things like Times New Roman and Arial and you'll be safe.

And what I want to leave with you now are some points to hit this home.

Here's a quote by George Bernard Shaw. The single biggest flaw with communication is to assume that it's taken place.

So as we think about newborn hearing screening and what we do as professionals in this EHDI business is we should not ever assume that our message has gotten across. Whether it's in the form of brochures or whether it's in the form of one-on-one dialogue with the patient or family.

So this comes from an actual patient right here in Little Rock. Please speak like a human. Make it better. Not worse.

So here are some tools I want to leave you with. The slide seems to have come out a little bit funny.

But what this should say is that here are five things to consider. The first would be to speak slowly. Teach back. Encourage questions. Plain language. And show examples.

And so what I'm going to do is show you some things that you can do right here, right now.

One of them is the teach-back method. If you've never heard of the teach-back method, it's frequently used in medical schools and we're starting to see it more and more in other disciplines.

This is a chance to check for understanding and if necessary to re-teach the information.

This is how it works. As you are talking with a family or parents, the first thing to do is to introduce new concepts. For us, this is the importance of talking about newborn hearing screening. You want to make sure that parents understand that this is not the end of the road. They need to follow up on this. You're explaining a new concept and addressing its importance.
And then what you do is you give the parents an opportunity to explain back to you what you just said.

If they didn't quite get it right or if they're stumbling on it, this is an opportunity for you to clarify. And then finally, you have them try it again. And you can do this in a way that does not insult them. Do it as you would in normal conversation. But that's the most important that you can do. Make sure that they walk away from your clinic, what have you, armed with the information that they need to make an informed decision. And follow up.

Here we have an example of a mother who probably just gave birth and says now I know what I'm supposed to do.

The other thing there, consider is another strategy called ask me three. It's so simple. You don't have to describe to the family what the ask me three strategy is.

But if you can have them leave with the ability to answer these three questions you're in good shape.
What is my main problem? Well, maybe the problem is there's a failed newborn hearing screening. What do I need to do? Why is this important for me? If you can get that family to walk away with the answers to these three questions, you will be in good shape and perhaps our lost-to-followup rates will decrease.

And finally, Nan and I spent a lot of time talking about readability and organization and so on and so forth.

There is a paper out there that describes a five-step methodology to improve the readability of your documents. Remember, that's just one of five aspects that we're trying to convey to you today.

Readability and usability. Let me walk you through quickly and then we'll be at the end.

The five-step methodology. Evaluate the readability of the original document.

The second step. Identify essential medical terms and scientific jargon for simpler redefining. We certainly recognize that there are words that should be in the parents'

vocabulary. We don't want to necessarily deviate that or dumb down the language in any way shape or form. And my saying dumb down is not a politically correct term, but that's exactly what we should not be doing.

If we need to teach the concept of ADR or OAE, then do so in a manner that briefly, clearly and simply describes what that particular test is. You'll be amazed when you've got parents who understand what that test is and is able to tell other people what that's about.

When you find that, revise your sentences. Think more creatively about how you might organization the information. You would go and revise the sentences and try to get them down to a 5th grade reading level. And remember 5th grade is that target for health information. The fourth step, evaluate the readability of the adapted document. And then finally do a comparison between the pre-adaptation and the post-adaptation.

They, these authors, they were able to successfully adapt, revise, their documents at a 5th grade level that did not detract from the content and the information of the materials that they revised.

So with that, those are our references. I think there may be some opportunity for questions. But I'll turn this back over to our host.

>> NANNETTE NICHOLSON: Thank you very much. That was wonderful information. We're right up to the wire, but we have a couple of minutes for questions. We had a couple of questions that were typed below.

One was is there a way to see the slides? Yes. This will be recorded and be available on the website.

And the other was regarding the reference available for the checklist. That's available on the reference here. And you can Google the checklist according to Nan and be able to retrieve it. I don't know if you had anything else Nan that you wanted to add about that.

>> NANNETTE NICHOLSON: Just that it is published in pediatrics. So it is readily available. I don't think that you'll have any trouble retrieving it. But if you do have any questions, you can always feel free to e-mail me, as well.

Are there any other questions?

>> It doesn't look like there are any other questions. I want to thank you all very much for attending your very first EHDI to your desktop webinars. There are some others coming and I'll get that schedule out to the NCHAM website and also out to the rest of you.

Ruth is asking to wait. She's asking for a couple of questions. Go ahead and ask your question and I can read them out to the group and give Nannette and Sam a chance to answer.

>> SAMUEL ATCHERSON: It looks like we have a question about going back to the three questions page. So the ask me three. I'll just put that up there. I'm looking for the other question that was being asked. Assuming that you can still hear me, we have a participant who has this question.

Any words of wisdom for working with parents who do not speak English and probably don't even have a third-grade reading level?

>> SAMUEL ATCHERSON: That's a good question. A tough one. I'm wondering if in that situation we've got to be thinking about interpreters. Unless you are able to adapt information at a level that they can understand or put it in their specific language. We do know from the EHDI website that many states often provide not only English brochures, but Spanish brochures.

And unfortunately we weren't able to analyze the readability of those Spanish documents. But I am aware that there are some readability formulas. But I am not an expert in that area. I do not speak Spanish in my everyday life. But it's certainly something that's open to evaluation and it's certainly something we should be thinking about.

>> Tami has a great idea that she shared. You may want to consider a focus group who speaks in the native language.
And you may be able to find someone through your local Hands and Voices group. That's a great idea, thank you.

I want to respect everybody's time because I know how busy all of you are. We'll let you go ahead and head out know. Thank you so much for attending this webinar. I hope you found it as useful as I did and that you're able to use some of the information that you learned today in your brochure development for your groups.

Thank you so much.

>> SAMUEL ATCHERSON: Thank you everyone. Take care!

>> NANNETTE NICHOLSON: Thank you!

(The webinar ended at 2:35 p.m. ET)