

The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy

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Dr. Sandra Baxter: Good afternoon. And thank you for joining us today to discuss "The Health Literacy of America's Adults." My name is Dr. Sandra Baxter and I am the director of the National Institute for Literacy. The Institute is hosting today's webcast and it is being brought to you live from Washington DC. The Institute, a federal agency, is charged by congress to provide national leadership on the issue of literacy across the lifespan. An important part of our mission is to serve as the national resource for adult literacy programs and as the clearing house for research and resources on reading, reading instruction and adult literacy. We are pleased to host this forum on the results of the 2003 National Assessment of Adult Literacy, also known as the NAAL. This assessment is the first to look at our nation's progress in adult literacy in well over a decade. This report was conducted under the auspices of the National Center for Education Statistics and the Institute is pleased to be working with NCES to share these findings.

The NAAL provides us with important information about background factors associated with literacy and the skill levels of America's adults. The study also offers information about the literacy needs of English language learners. More than a year ago we began a national conversation around the NAAL and these important findings. Today we continue that dialogue as we address and engage our expert panel on the NAAL's Health Literacy Results.

The NAAL incorporates the definition of Health Literacy that was developed by the Institute of Medicine and the US Department of Health and Human Services. That definition is found in the objectives of Healthy People 2010. It defines Health Literacy as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions. Health Literacy is important for all adults; it is not

just important for those who cannot read. It is also and can be an issue for well-educated adults to know and understand health information needed to make everyday decisions. Making good decision, health decisions, depends on having a high level of reading and comprehension skills. Just think about the last time you picked up a health magazine or pamphlet while sitting in your doctor's office. Or a decision you had to make when buying on over-the-counter medical medicine. Or how you felt when you had to give advice to an aging parent on issues about end-of-life care. All of these activities required and are facilitated by the ability to read and understand written and printed information. We look forward to an engaging discussion today about the health tasks for the 2003 assessment, how well adults who were tested performed, and what this means for our general population.

We are pleased to be joined by two national experts this afternoon; Dr. Sheida White is here from the National Center for Education Statistics. She is the project officer for the NAAL. And we are also joined by Toni Cordell, who is an adult learner who recently served as an expert panel member on the joint commission. The commission is an independent organization which accredits and certifies health care organizations and programs in the United States. Toni is also a nationally known speaker about health literacy and she shares many of her own experiences in this area with us.

We are very sad to announce that Dr. Ian Bennett, an Assistant Professor at the University of Pennsylvania School of Medicine, is unable to join us today. He has had a family emergency and he has our best wishes and good thoughts as he is tending to that.

Again, welcome to our panelists and to you, our online audience. Now we are going to begin today with Dr. Sheida White who will explain the findings of the health literacy assessment. Sheida, welcome.

Dr. Sheida White: Thank you Sandra. Good afternoon. I am pleased to be here today and share findings from the Health Literacy Component of the National

Assessment of Adult Literacy. This is the first national assessment, large scale national assessment ever that was designed specifically to measure health literacy. So we are all very, very excited at the results.

Ian, if you are watching this, I wish you best of luck.

In this slide I am going to talk about a few topics that you can see here. My focus will be on the results and how literacy is distributed across various groups and subgroups of adults. The first bullet, we are assessing literacy, English literacy of US adults. I emphasize the word English because there are a lot of people out there who are highly literate in other languages but they are not, but not necessarily in English. We have a nationally represented sample of 19,000. Of these 19,000 adults approximately 18,000 live in households and about 1,200 in state and federal prisons. The last bullet, we have four scales. We will be able to, indeed we have reported trend data, we reported changes in literacy for three of the four scales, prose, document and quantitative. But health literacy as you know was the first time that we administered it in 2003 and so we have to wait for the future assessments to see changes in performance.

Next slide is our definition which is pretty straight-forward. It is really not that different from our definition of [general] which is prose, document and quantitative literacy. The only difference here is that we are going to, the reading and comprehension of information is applied to health-related material as opposed to general material.

In the first slide, first bullet, in 2003 we had a total of 152 items. And of these 152 items, 28 items were health-related. In fact they were designed to be health-related. And 2 of these 28 came from 1992 so we had 26 brand new health-related items in 2003. Just to give you examples of what we mean by clinical, prevention and navigation of health care system, an example of a clinical task would be for example filling out a patient form. An example of prevention would be following the guidelines for age related preventive measures like having annual mammograms if you are over 40. And the navigation of the

health care system, an example of that would be understanding for example what a health insurance plan will pay for.

I do want to remind the audience out there that this assessment is an assessment of written and printed health-related materials. It is not an assessment of comprehending all language or speaking. It is also neither an assessment of how much you know about health issues like what to do in case you have high blood pressure. It is not an assessment of whether or not people can understand technical medical terms or anything like that.

Next slide gives you an example of a health item. We classified this into our prevention category. It also is an assessment of document literacy. As you can see here the question asks participants to copy three food sources that contain Vitamin E. And we considered the answer to be correct if the participants listed any three of the following foods, I don't know if you can see them but I am going to read them to you – wheat germ, whole grains, eggs, peanuts, organ meats, margarine, vegetable oils or green leafy vegetables. This assessment task is used and is on our website.

I do want to take a moment and talk about a request that I hear coming from you very often. And that is requests for the 28 health literacy items. I know it is very important to your work and to your research to have these items but there is a problem for us releasing these items. And here is the problem. It is not that we are trying to be malicious or anything like that. Whenever you call and we say no we can't give it to you, the reason is that these 28 health-related items are embedded within blocks. We have blocks of items; each block has about 10 or 12 items. And so there are about 2 or 3 health-related items embedded in these block of items. There are 13 of those. 7 of these blocks were developed for the 2003 assessment and nearly all, 26 of those 28 items are in those 7 new blocks of items. Now in order for us to establish trend to the future now, the (inaudible) tell us that we need to have at least 6 blocks of items. So that only leaves one block for us to release. We need to keep those, if we were to release all of the items including the ones in the new 6 blocks than we can't turn around and use them again in the next assessment. And so here is what I think I

can do for you. I can, I have already decided which block of item was contained, health literacy items, most of the health literacy items and I am suggesting that we release that as block number 8. Another thing is for you to come to my office in Washington if you like and look at items. You can come to my office and look at the items but you won't be able to copy them or you won't be able to take those with you, but you can look and see what they look like.

And then the third thing is to go on our website and look at the released health literacy items that we have on our web – there are 6 of those I believe. Now here is if you wanted to do that, go on our website, here is what you can do. Here are two print screens. The one on the left is the NAAL, what they call Test Questions Tool. It is on our website. Now this tool will give you access to the questions and to the answers from the 1985 and 1992 assessments that are released to the public. We have a total of 109 questions on our tool. That is a lot of questions in this question tool, and as I said, including 6 health-related items. So if you have any difficulty accessing these items please feel free to send me an email and I will guide you, Sheida.White@ed.gov.

So we can move on to the next, oh let me just stay on this for a moment. I think it is a little bit hard for you to see the second slide, but if you, let's say you wanted to look at the items that I just presented to you earlier about Vitamin E, look at the slide on your right. You will find interesting information about this particular item. You will find out what year it was given. You would find out what other literacy scale it is classified as, is it prose, document or quantitative. You can find something that we call Task Demand. What is the cognitive and the (inaudible) requirement of this particular task? And you will also find out what percent of people answer that particular question correctly. In this case, I can't see, it is 60% or something like that. So you get all of that information for each of those 109 items that are on the website.

Okay. Did they get to see the header for these slides? I guess they do. In this case, the title is Health Literacy and Literacy are Closely Related. That is what this slide says.

Dr. Sandra Baxter: They do see the header.

Dr. Sheida White: They do see, okay, thank you. Now health literacy is, as many of you are aware, is very closely related to prose, document and quantitative literacy. And that is because all of these forms require the ability to use printed information to function in society. So in other words, health literacy is not a distinct set of tasks. It is not a distinct set of materials or a set of skills. However, there is a, despite the high correlation between prose, document and quantitative and health literacy, which is I believe in the 80s, the correlation is not perfect. And that suggests to us that there are some additional, there are some conceptual differences among the scales. And we see this also with prose, document and quantitative, there is a high correlation actually between prose and document literacy, the correlation is as high as in the 80s, but we don't say that document literacy is the same as prose literacy in the same way that we don't want to say that health literacy is the same as document literacy because they have high correlation in the 80s. So I try to articulate some of the differences that we see between health literacy scale and other scales.

The health literacy items, they have a lot of health-related vocabulary. And of course every vocabulary has an underlying conceptual understanding and knowledge about; it is like a schema that is much broader than the vocabulary itself. And these are common health-related vocabulary. They are not highly technical. But we considered within common range things like diabetes or even hypertension. Then another thing that is specific to these items is that they require understanding of the genre of the structure of health-related materials, for example, health insurance forms. There is some commonality across health insurance forms even though they are different. And also the workings of the health care system, for example understanding the notion of co-pays. So that is how we think the health scale is different from the other scales.

So let's go to some of the interesting results. I have selected a few results that I thought you would be interested in; this doesn't exhaust all of the results that we have. So let's go to the first slide and here this is a little bit complicated so I am

going to take you through it because it covers a lot of information here. So let's just focus for a moment on Below Basic in health literacy. This slide shows that 13% of all adults and by 13% I mean that 10% in the Below Basic and the 3% who took the supplemental assessment. This is what I call 13%. These are the people in Below Basic in Health Literacy, that 13%. And this translates to 30 million, it is 13%, it translates to 30 million adults who are in Below Basic Health Literacy. That is a large number.

Now this 3% are the adults, as I said earlier, they are at the bottom of the Below Basic Health Literacy level. So these are people who did very poorly on the NAAL core assessment so we had to [route] them so that they can take the supplementary assessment. So this 3% represents 7 million adults. And then we had another 2% which represents 4 million adults who couldn't take the assessment at all. We have interviewers who are actually bilingual in English and Spanish and then they go to these homes and if they cannot communicate with a person about their age or education or anything like that in English or Spanish then the case is closed. There is no way that we can work with them. So that is what the 2% represents. So all together we have 11 million adults or 5% we call Nonliterate in English.

I would say that there is another 1% that you don't see here, people who had mental or cognitive disabilities and we did not want to include those categories in the nonliterate in English because we don't know, they could have been able to read, so they are not included in the results. Actually the results that you are going to see today, they do not include the nonliterate in English category at all, the 5%.

Okay, now let's see the distribution of health literacy of American adults in all of the levels. So as you see here, the majority of adults, that is 53% have intermediate health literacy. We have 12%, an additional 12%, who had proficient literacy. In other words you can say that 1 in 9 adults is proficient when it comes to health literacy. One way to think about it. 1 in 9 adults is proficient in health literacy.

Among the remaining adults, 22% had basic health literacy and 14% had below basic health literacy, which as I said earlier translates to 30 million adults who have difficulty – these are the people who have difficulty understanding and using written health information with any accuracy or consistency.

Okay let's move to the next slide. I should have said nearly, I said approximately, it is really nearly because it is actually 77 million. It is nearly 80 million adults may not be able to successfully answer those questions. They may not be able to interpret an over-the-counter drug label; they may not be able to know when a child should receive a vaccine from a chart. They may not be able to use a body mass index, the BMI chart. When I said they may not be, what I want to say is that they have less than 2 out of 3 chances of being able to successfully respond to this. That is what 67% means, 2 out of 3.

Okay. Next slide shows you how adults – this is very interesting. This tells you how adults with Below Basic health literacy are different from adults in the population as a whole. So the first column, there is the percentage in the health literacy below basic level. So for example, 51% of adults in the below basic health literacy did not graduate from high school. So education is a very strong correlate of literacy based on this. Now the second column shows you representation in the general population. So adults who did not graduate from high school are 15% of the entire population. You can see the difference in there. So adults who did not graduate from high school are much more over represented in the Below Basic category of health literacy.

The next slide, again, as you might expect average health literacy increases with each now, we see each higher level of educational attainment. In other words, as the level of education goes up, the level of proficiency goes up and the level of below basic goes down. You can see that beautifully in this chart from top to bottom. So among the adults who did not complete high school, the first row, 49% had below basic health literacy compared to 15% as I said earlier who ended their educations with a high school diploma, below that.

Now let's for a moment look at the college graduates. Not all college graduates are in a proficient level either, far from it. Among those who completed four-year degrees, for example you see 13% are actually in basic and below basic, 10% in basic, and 3% in below basic in health literacy. 13% of people with four-year college degrees are either in basic or below basic when it comes to health literacy. Now one thing I want to remind you of is when we talk about college graduates, we are not talking about necessarily about recent college graduates. These are people who could have graduated maybe 40 years ago, entire population.

This is very important because this got a lot of coverage in the news when we talked about education and literacy. The relationship between education and literacy is a very complex one. The immediate inclination is to think that if you have more education than you are going to do better on this test. And you are going to have better health, improved health. I guess that is what I am really thinking about, the relationship between education and improved health. But that may not necessarily be the case. And I am hoping that some of you out there that are researchers are going to look into this a little more carefully.

What are the, is it possible that maybe people who have poor health have low health literacy and not necessarily all the other way around? Or could it be related to income or other factors? We need to explore these issues and we have not done this and NCES and I am hoping that some secondary analyst will explore these issues further to see the correlation, to try to understand why is there such a strong correlation between education and health literacy.

Now let's look at the next slide. From this slide you see that Hispanics have significant, I should say not Hispanics but I should say people who speak Spanish only or that speak Spanish with another non-English language; those individuals have significant health literacy challenges. 55% are at below basic and 22% are at basic.

Let's look at the next slide which talks about the relationship between self-assessment of overall health and health literacy. So let's look at the first row for a moment. 42% of adults with below basic in health literacy and 27% with basic in health literacy which is a total of 69% reported poor health. Now take a look at the last row. You see that only 8% of adults with below basic in health literacy and 17% with basic in health literacy or a combined score of 25% reported excellent health. So this data shows that adults who are most in need of health literacy are the ones with the poorest reported health which is very interesting.

Now let's look at the percentage of adults at each health literacy level by age. As you can see, adults who are 65 and older, they have the highest percentage, 29%, in below basic health literacy compared to all of the younger age groups. A big difference. We really don't have an explanation for the difference in the literacy between older and younger adults. And this is another good question to explore further. We do know, let's tell you what we do know, I'm going to tell you what we do know. We do know that few older adults report having poor secondary education. So as a whole the country we go to college more every year, more educated. We also do know that older adults report having more disabilities than younger adults especially with vision, hearing, and possibly declining memory or other cognitive abilities. But we don't know that this education and disability alone explain the difference that we see here. We hope this is going to get explored further.

Next slide is also interesting. It compares the use of internet to find information about health issues among all age groups. Now again here, generally speaking, adults in the older age groups were less likely to get health information from the internet. The percentage of adults who were 65 and older who reported getting no information about health issues from the internet is 77%. It is by far the highest percentage among all of the age groups.

I do want to let you know that we have finally released the public use and the restricted use data files. They are on our website. There will be instructions for installing the data from the electronic code book. You can get that on the website. If you wanted to have access to restricted data files there are

information on our website in terms of how to obtain the required license. Then what else can I say about this, let's see. There are differences between the public use and the restricted use of the file. Public use data files do not contain data on the oral reading fluency which we call [SAN]. They don't have that. And also the information in the public use data files is not as detailed as it is in the restricted use data files.

One more thing, one additional related issue I want to mention here is that a couple of weeks ago we had a training for people who wanted to know how to use the NAAL Data. We are hoping to have more of these trainings in the future. Check our website periodically. There will be information on future training and also I understand that we now have a discussion list going so you can be on that as well.

We have, I just wanted to tell you in closing what other reports you should be expecting. There will be a report on small area estimation. We will be reporting indirect estimates for all 50 states and all counties which is very exciting. And we hope to release a report on oral reading fluency and the results of the supplemental assessment we also called (inaudible). There is a report that I am writing; it presents a new theory of functional literacy. Just to give you a little preview it states that performance on everyday literacy is a function of task demands. These are all very complicated but needs to be described, [text] and [tax] characteristics and respondent's skills. And we had this quantified, defined and actually validated with a multidimensional methodology. So that is also very interested for you guys who are interested in theoretical and methodological and psychometric issues.

This is all I have to say. These are the reports that we have published in the last few months. Thank you so much.

Dr. Sandra Baxter: Thank you Sheida so much for that wonderful overview. To our online viewers we will be addressing your questions at the end of these presentations. Please use the text box below to enter your questions and then

click on the Submit button. Now let's turn to Toni Cordell who is going to share here experiences with us as a patient and as someone who is an educator on health literacy issues. Toni, welcome.

Toni Cordell: Thank you, Dr. Baxter. Good to be with Dr. White. Interesting story. I graduated from high school reading at the fifth grade level. By the way I didn't do that to myself on purpose. I could read well enough to get by but not ahead. I could read well enough to graduate from high school and not well enough to get a real education. I read well enough to read a couple of Dr. Seuss books to my children and not well enough to read a book on how to nurture those children. I read Dr. Seuss books to my children but, I think I just said that. I also could read well enough to see the difference between a can of cat food and a can of tuna fish, but I couldn't read and follow the recipe in order to prepare that tuna fish. I could read well enough to get any minimum wage job and not get a real career. And I read well enough to sign my name to legal papers but not well enough to understand that those legal papers had very costly consequences.

So I read well enough to get by and not ahead. Let me try to explain the way I read. When I read I named one-word-at-a-time. They were just lines and circles on pages. By the time I got to the end of the sentence I could hardly tell you what any detail was or did I have any comprehension of what I had just named. Also my fingers read before my eyes did. Now that might not make sense to you, but if you stood in front of me and handed me a single sheet of paper my fingers could tell me that. And I might read off of that paper to myself. But if my fingers told me you added another sheet or two, therefore there were several sheets of paper there, I wouldn't read in front of you even silently. Now I know very clearly this is flawed thinking but I so feared that if I tried to read silently in front of you that you would be able to tell how slowly my brain was working. I couldn't handle that kind of humiliation. So I wouldn't read in front of you, therefore my fingers read before my eyes did.

Now I finally had a challenge in the medical system because of my poor reading skill. About 30 years ago I knew I needed to see my gynecologist and I

did so. During the exam the doctor said, "Oh that is an easy repair." So we set up a surgical date and I showed up at the hospital across the desk from the admissions clerk and she pressed paper after paper after paper before me. Now I know that I have to sign those papers in order to get my easy repair. So I did as I was told. Signed everything. Didn't read a single sheet. And by the way, when I was with the doctor I didn't ask any questions.

So there I am, I go in for the surgery and thank goodness it was successful surgery. However during the six months follow-up exam the nurse comes bounding into the office and says, "Hi, Toni, how are doing since your hysterectomy?" Well excuse me, but a hysterectomy means you cut something away. You cut something out. I was flooded with humiliation and silent shame. I did not say excuse me, hold it, let me get clarification here. I didn't want her to know; I had not understood what that easy repair was. I acted as normal as I could on the outside and simply said I am doing fine, thank you. But it was quite frightening in retrospect. Now fortunately I had the three children we wanted, I wasn't planning on more pregnancies, but that could have been a tragedy beyond measure.

So do you understand that I feel like I am on a first name basis with failure? It is around every corner waiting to attack me. Claws in my shoulders, holding me back from opportunity that I would really like to have. Not being able to read well closes many doors. My favorite word is opportunity. And I hate that I have missed many opportunities because of my poor reading.

I also want to share a very positive experience I have had with the medical profession. About 5 years ago I was sent to an urologist at Emory University to continue to do some of the repairs that needed to be done. Dr. Neil Galloway is a perfect example of a physician that knows how to communicate. During my very first appointment in the examining room Dr. Galloway came in while I was still dressed, technically we were both still dressed, I think that is an excellent approach to first meetings by the way. And he asked me many, many questions trying to evaluate what was and what was not happening correctly. When he got the answers he needed he let the nurse know to prep me. So as

he left the room she helped me get ready. Draped in one of those wonderful little paper drapes, excuse my sarcasm, in the stirrups, that horrible table. When he arrived back in the room he explained before he laid a hand on me what he would be doing. And he warned me as he was doing the exam what would be uncomfortable and what he was doing.

Very good about communicating. And then when he left the room, instructing the nurse to get me ready for the next phase, she helped me get up off the table, I got dressed and sat down and waited for him to get back. When he came back, now again, chair to chair, knee to knee, both dressed – I am no longer feeling that vulnerability and exposure, that nakedness that we feel in the doctor's office under those circumstances. And then Dr. Neil Galloway not only told me what he had found and what needed further testing but then he also said, and I love this, he drew pictures also. Now I know where the organs are in the lower abdomen. I know the basics of that. But he said we are going to need to cut here, we are going to need to stretch there, we are going to need to stitch here. And he drew me Picasso-ish pictures. So I wish I had kept those; they could have made a good example.

By the time I went into that surgery I had a very good understanding of what needed to take place even though I am still not very good at asking questions, he knew how to communicate. And he did it very well. Because of these things I believe that every patient has a right to be a full partner in all medical decisions. And that requires crystal clear communication with mutual respect.

When my husband of 30 years was in the last month of his life, prostate cancer had metastasized into the bone. Carl was an extremely high IQ person – good education, college education. Bright, interesting, well-educated. I was faced with dealing with the insurance papers. I won't go into a diatribe about how awful that is but I hated it because I still loathe paperwork.

Another factor I remember very clearly. One of the times we walked out of a doctor's office this brilliant man said to me in a kind of a sheepish puppy-like

voice, almost child-like, "Toni, what did she say to me?" This is an educated man. But he has been under oncologist care for over a year. He is not functioning at peak performance, so it really doesn't matter if you have a high education and a high IQ; you walk into the physician's office with 100 degree temperature, flu symptoms or cancer or whatever life threatening or not, you are not functioning at peak performance. So we are vulnerable.

What is clear to you is clear to you. The words we use are important. But there is more to education and communication than words. Let me give you an example of what is clear to you is clear to you. Carl was in the media and in the San Francisco Bay Area when Nelson Rockefeller was on the Vice Presidential campaign, I think he was on the Nixon ticket, this was quite a ways back, some of you might not remember. Carl and his cameraman were assigned to go get a part of that story. So Carl and the cameraman pulled the car over to the side of the street on the route where Nelson Rockefeller would be driving though and Carl clearly communicated to his cameraman – let's pull over here, you get out the shotgun and shoot him from the top of the car. Carl and Bill understood exactly what was meant. However, the two secret service guys walking by had a different perception of what those words meant, and they were detained by the way.

Now Carl and Bill knew that a shotgun was a shotgun mic which is a long mic picking up directional sound. Shooting – they were shooting 16mm film. They were not shooting bullets. Just an example of what is clear to you is clear to you.

And when we are sent to the pharmacy to get a medication, thank goodness different pills are different shapes, different sizes and different colors. Because there are so many different prescriptions we can take. And if a person is taking more than maybe three, how do they differentiated? I don't read the outside of that bottle because there are funny little words that mean something on there. I know how to read the doctor's name; I know how to read my name. most of the time I know how to read what it tells me to do. However some of those prescriptions have inserts that have words on them in a font that you would

have to have 3-year old eyes to read. This is not a 12-font, which is what I want. And these words are way beyond my understanding. I don't have a medical education; they are medical-ease. So again, another way to be vulnerable.

So I am asking you to be aware of the fact that those of us who walk into your office or need your care may not be functioning at full peak. But not just those of us who lack an education or who don't read well. Any human being can find themselves very vulnerable, needing care.

Thank you Dr. Baxter.

Dr. Sandra Baxter: Toni, thank you for sharing that very compelling story with us.

I want to remind everyone that you can submit your questions online now and we will talk about them. We already have a number of questions and Toni I would actually like to begin with you.

Toni Cordell: Alright.

Dr. Sandra Baxter: From a healthcare provider in Bedford, how do we begin to use this information in clinical practice with older adults? Can you give us two or three words of advice on what to do?

Toni Cordell: I understand the research indicates that when we hit 65 we seem to come across as non-compliant, many going home and not taking their prescription correctly. I am not 100% sure as to why that is happening. I do know that I still feel overwhelmed a great deal. And maybe at 65 we often end up taking more than one prescription. I wish I had a simple do A, B and C. I am asking you not to just listen to the words we are saying but to listen to our heart. My generation and those before me often put you on a pedestal. We often will

not ask the correct questions. And there was a program sometime back, well, it is the Ask Me 3 program. If we could train the patients to ask three major questions we could make your life easier so you could then help that patient by teaching the patient the questions. And the questions are basically, "What is my main problem? What do I need to do? And why is it important to me?"

Since we haven't had the opportunity to train patients across the country that gives you something else to do, train the patients. Recently I also saw Dr. Pinkus give a lecture and one of his slides indicated that in the past healthcare has often taken place from the shoulders down. And he is now suggesting that in behavioral medicine being integrated into regular medicine we need to take into consideration the entire person. Let's not guillotine off the head. Because what is going on in the head is affecting our whole body. And possibly a great deal of the problem of what is going on in the body at age 65 is a lifetime of experiences that cause us to think a certain way.

I apologize for not having an easy A, B or C answer.

Dr. Sandra Baxter: That is alright. You know one of the things that I have found helpful too is, particularly with older patients (inaudible), taking a family member along.

Toni Cordell: Absolutely.

Dr. Sandra Baxter: And also writing down what the doctor tells you. Have doctors who encourage that. So that is just a couple of ways. Sheida, there is an interesting question here from a viewer. This one is rather long so I will read it to you. The results from the earlier NAAL study promoted the number 90 million who had inadequate literacy skills to function in society. This was very powerful in gaining support for health literacy initiatives. From the 2003 data, what is the number that is considered inadequate? What are the number, what is the number of individuals considered inadequate in their health literacy skills? Do

we include below basic and basic levels in that count? Is intermediated considered adequate skill level? And do we include the 5% nonliterate and 1% cognitively disabled in these numbers?

Dr. Sheida White: What is inadequate? Let's just look at what individuals who are below basic, especially at the very low end of the range. I actually gave you an example of those questions that they cannot do, for example they cannot – I shouldn't say they cannot – they are less likely to be able to read and understand an over-the-counter drug label. So is this an adequate or not, it is not really for me to say. I can just tell you what these people are and are not able to do. In general, let's look at it a little bit more generally, people who are/have below basic level, especially at the low end, these individuals cannot read connected text. They cannot read continuous text. They cannot read sentences and paragraphs. They can read individual words or phrases, like what you were saying, when you were reading you were reading one word at a time, but you weren't putting it all together, is that correct?

Toni Cordell: Correct.

Dr. Sheida White: That was very helpful to hear that from you because this is the level of literacy that that they have. So if you want, depending on what their goals in life is, what is adequate is really is an individual decision. What they want to do, what they want to accomplish with their life. Being able to read a telephone bill and pay the bill is a critical functional skill. If you have to do that in your life to get by then it is something that if you cannot do that then it is inadequate. So I would say what determines what is adequate or inadequate is a function of individuals and what they want to, what goals they want to accomplish in their lives.

Dr. Sandra Baxter: Another question. Do the numbers suggest that the state of health literacy is any different or worse than the state of literacy itself in America? In other words, do a greater percentage of Americans have inadequate health literacy skills than general literacy skills?

Dr. Sheida White: As I said earlier, there is a very high correlation between general literacy and health literacy. The correlation is something like 0.86 I believe. So we do not have data showing that people with general literacy are lower in health literacy or vice versa. We see a very high correlation. They seem to go hand in hand. Now that doesn't mean again that they are the same thing. But they go hand in hand. One goes up, the other one goes up. One goes down the other one comes down.

Dr. Sandra Baxter: Okay. I have a question about the availability of the data. But before I ask that question I just want to remind our viewers if you look at the box at the bottom of your screen you can click on the button there to download the slides if you would like to today. Sheida, another question. Is there sufficient information in the data files at NCES, the online data files, so that a researcher can replicate the complete methodology used to assess health literacy? If not, why not and when will that be available?

Dr. Sheida White: To replicate the complete methodology I'm afraid is not an easy task. This methodology, the NAAL methodology is highly complex. It depends on what aspects of methodology maybe we should ask some further questions. It depends on what aspect of methodology that you are talking about. Is it analysis or is it data collection? If you are referring to methodology as it refers to the analysis, you can certainly do what we did, use the AM software and analyze the data exactly the way we did; there should be no problem with that. And as I have said before, we have directions for that on the website. And you can give us your name, by all means and we are collecting those names to offer another training session. And we can make sure that you know how to analyze the data. You can replicate those analyses for sure, if you are talking about analyses.

Dr. Sandra Baxter: Okay, great. Thank you. Another of our viewers who is a healthcare provider suspects that some of her patients are struggling with reading and that there are others who can't read or write. And her question is whether or not she should directly address this issue with them by asking whether

or not they can read and write. And seeking to help them with their medical insurance forms she is concerned about embarrassing them. Toni do you have some advice on how to approach this problem with a patient when you suspect they have it?

Toni Cordell: Yes, thank you. First of all, please don't ever ask anyone if they can read or write, even a 3-year old. I went to a [LABAC] program when I was in my late 40s and had a tutor. So my reading was dramatically improved. However, if you had asked me prior to that if I could read, I probably number one would have bit your head off because I would have felt the shame of that; and number two I would have said yes because I could read well enough to get by. So don't ask people. There is just too much humiliation in that.

Insurance forms – oh please help me with my insurance forms. But there is a way to ask. There is a way to say, "Would you like us to assist you with your insurance forms. We would be happy to do that." So you are providing me with a service rather than judging my poor reading level.

Dr. Sheida White: Can I just say something? We, of course, we are focusing on individual's skills in this case but let's not forget that a lot of these materials are not all well written either you see. You could have multiple PhDs and not still be able to read and understand some of the government documents, and actually many government documents or health-related documents like the inserts that you showed. So there is room for the publishers of health-related materials that are in the audience there too to pay attention to this as well and make sure that the readability of the materials is tailored to the target audiences.

Dr. Sandra Baxter: You are making a very important point here. Because it isn't just an issue of the health literacy. It could be an issue of document literacy.

Dr. Sheida White: And the materials that are used.

Dr. Sandra Baxter: Right.

Dr. Sheida White: Exactly.

Dr. Sandra Baxter : Toni, I see you had a [point to make for us].

Toni Cordell: Yes, I met a PhD in Michigan who teaches health literacy to medical professionals. And before she became an instructor, when she had her own practice she talked about the fact that she had a test. If the literature ended up being thrown away in the parking lot or littering the parking lot, that literature was not acceptably done. Because if you can read the literature and you can understand the literature, most likely you are taking it home to either re-read or share it with someone else. If you are dumping it in the parking lot or in a receptacle in the parking lot, chances are you just determined that you cannot read that and so why bother with it. And I love that about her.

And one other thing I was thinking about a moment ago. When we who are not dynamic academically walk around, I can blend with you fairly well. I can pass for literate fairly well. If I went into a room in a wheelchair you would automatically know that I was challenged in some way. But when I walk into a room with this hidden problem up here, people make assumptions that I am as educated as they are. And so it just creates an invisible, unintentional secrecy. And so the medical practitioner is given an extra burden in having to deal with us. And I apologize to you for that because it lays at your feet having to figure out what to do with us. And we are overly sensitive an awful lot of the time. Very few of us will say, "Excuse me but I am going to need your help in reading this."

Dr. Sandra Baxter: Yes, I think that is a problem I think also. It goes with a more general problem that most people don't like to challenge their doctor.

Toni Cordell: Correct.

Dr. Sandra Baxter: And so there is that always the give and take that is necessary.

Toni Cordell: Mutual.

Dr. Sandra Baxter: The mutual respect, that is right. Is there something we could be doing to lower the stigma so that people don't feel so embarrassed about this problem?

Toni Cordell: I don't know if that is possible. There are so many components in our human life where we judge each other. Whether we are judging each other so that I can feel really good about myself and therefore judge you less or whether we have just been raised in a certain way that we have condemned another because they don't reach our standard. I would love to feel less stupid. After all, I sat in class for 11/12 years. I finished high school so I sat there just like you sat there. And yet I didn't get it. My self judgment is pretty heavy. My self loathing is pretty heavy. Even if I could get rid of that it would be (inaudible).

But like so much of our judgment it is based false information. So as long as there is false information and perception, I suspect we will always be judging each other.

Dr. Sandra Baxter: So it really speaks to the need of educating the public about the problem and helping people to understand that this is not an individual's flaw or deficiency.

Toni Cordell: Yes, I don't believe, you will never convince me that a child goes to the second grade and goes to the teacher, "I don't care how hard you try, I ain't gonna get it." No, I believe we are created curious, we want to get it. We want to succeed. Those who are dropping out I believe often times are voting with their feet and saying I didn't get it. They are not necessarily saying the teacher didn't present it correctly. There are many reasons why they didn't get it. In my case, learning disability, memory problems, whatever it was. But if we are going to claim to be educators then we have to find a way to impart that knowledge so that that human being can be all they were designed to be. I hate the limitations in my life.

Dr. Sandra Baxter: Just a couple of more questions here about technical reports about the NAAL itself. For individuals who spoke English/Spanish only or another foreign language, did they receive the assessment in their native language?

Dr. Sheida White: They had a choice of receiving, now the assessment let me be clear about this. The assessment itself is all in English because this is an assessment of English literacy not of Spanish literacy. However we had, the background questionnaire was offered in English and Spanish and the easy core items, the instructions to those items were offered in English or Spanish. And the supplemental assessment also was offered in English or Spanish. In that case they could also respond in Spanish. So they had an option and based on their desire the interviewer gave him one or the other form. Does that answer the question?

Dr. Sandra Baxter: Yes, I think it does. Toni, for you. Someone writes, I have given health literacy presentations to physicians. They have been very interested in the topic but don't see it as a problem in their practice. How can this data be used, how can these data be used to help physicians understand that low literacy, low health literacy patients are in fact a problem in many practices?

Toni Cordell: In order to not have a patient that is struggling like I have, you would have to be practicing on another planet. The statistics very clearly show us that a full ¼ of our population is not reading above the fifth grade level. So I am going to make a guesstimate and any of them can come and challenge me; I am happy to be challenged. I am going to guess a minimum of 10% and probably 20% are not getting the written material and missing some of the verbal communication. Now if they are in a part of the community where education has been lax, then their clientele, their patients may rank in higher numbers of poor literacy. So any physician, and I don't care if he is in the most wealthy section of town, he or she, see I am from the old school – they were all male doctors in the old days – thank you that they are not all male doctors today. There is just no way, unless maybe a plastic surgeon to the very, very elite, I don't know. But you have got to have a patient or two in every practice that is lacking educational skills, maybe to one degree or another. Maybe they are not fully illiterate but again let me take you back to my husband. IQ in the top 1 percentile in the world, dealing with cancer, fatigue, needing morphine to function. He may be intelligent and highly educated but he is ill. So the doctor has a responsibility to rethink whether or not he has patients who need extra help.

Dr. Sandra Baxter: And a related question, what are the implications for informed consent for people at basic and below basic literacy levels.

Toni Cordell: They give me the clipboard and I sign and I hand it to the person and I said, "By the way I didn't understand this." I love to do that because number one I want them to know that I didn't understand it because there are funny words in the HIPPA and that sort of stuff. I don't even know what HIPPA stands for, I just know that we talk about HIPPA. And sometimes the young lady will just look at me and other times they will joke, "Yeah, we don't get them either."

The point being that the moment I have handed that signed piece of paper over and said I don't understand this I have just put the legal ball into your court and said if I have a problem and want to sue you, I just warned you. Now I am

not telling you I want to sue anybody, I haven't done that with any medical professionals, I just want you to be on guard. It is a piece of paper and it virtually can be ripped apart in the court of law if somebody decides to do that.

Dr. Sandra Baxter: The issue really is, once the patient signs that they are not able to understand what it says and it isn't carefully explained the implication is that the doctor could have a legal problem, right. Alright.

Sheida, a question for you. How would you categorize the impact that the NAAL health literacy assessment has had on the health and literacy fields. What indicators if any do you have that these findings are changing the way patients and healthcare providers relate to each other. Do you know anything --?

Dr. Sheida White: it is too new. It is too new the assessment. The results were just released a few months ago. And we are still continuing to analyze the data and hopefully in five or ten years we will see some dramatic changes.

Dr. Sandra Baxter: Okay. And do you know if there are plans underway for assessment to determine if the release of these findings have had an impact? Or really is this the kind of study that gets funded by other sectors? Studying the interaction between the doctors and the patients?

Dr. Sheida White: We don't have any plan for doing any. Actually I don't think I have any plans for doing any additional analyses. So it is up to the secondary analysts to do whatever they want to do. NCES does not have any plans.

Dr. Sandra Baxter: But that certainly is an area that should be looked at and so I think encouraging researchers to think about those topics is really important.

Dr. Sheida White: Exactly I think. We really are counting on you to carry the ball.

Dr. Sandra Baxter: You know I think that is probably an interesting point that we need to make here. That so often these national assessments gather so much rich data and it is not data that we in the government get to analyze at a very in depth level many times. So we are really encouraging by making those data files accessible to the public and to other researchers, we are encouraging the secondary analyses.

Dr. Sheida White: Exactly. And we provide data and training and we answer your questions and whatever we can do to help. But we are just not capable of analyzing all of the, and answering all of the research questions that are out there.

Dr. Sandra Baxter: If you are interested in more information about the public use data files or secondary analyses, Sheida would you please just share with them the email address, the website address that they can go to.

Dr. Sheida White: I think it is in there in the last slide.

Dr. Sandra Baxter: Okay.

Dr. Sheida White: The last slide contains that information.

Dr. Sandra Baxter: Okay, so at some point I am going to ask that we put that last slide back up so that our viewers have an opportunity to write down the email address and the webpage address if they didn't copy it before. So let's turn back –

Dr. Sheida White: Yes, it is on the top in here. You see, the header of the last slide.

Dr. Sandra Baxter: Okay, thank you for putting that up. Let's turn to our next question. Okay. I understand that what is adequate is subjective. But they came up with the 90 million figure last time. What is the comparable figure with the 2003 data? So was there a comparison between the 1992 and the 2003 data?

Dr. Sheida White: Well first of all we re-analyzed the 1992 data based on the new performance standards that the academy developed for us in 2003. So yes, it is possible to compare the 1992 and that is what we compared and the results are based on that comparison in our recent reports. How they came up with, what was it 90 million for –

Dr. Sandra Baxter: 90 million who were –

Dr. Sheida White: I don't exactly know what exactly that refers to but one thing you need to keep in mind is that in 1992 we had a different system of performance levels. We had 5 levels and now we have 4 levels. And in addition to that in 2003 we routed some of the people to a supplemental assessment. In 1992 we had 5 levels. Level one was huge. And so what happened is that we didn't really tease out people with different levels of ability we just put them together in one category called Level one. So we tried to, so if somebody for example couldn't read well, couldn't understand what they were reading it was very difficult to tell whether these people didn't have inferential skills or comprehension skills or they just didn't have the basic word level skills. So that was the whole purpose of having a supplemental assessment so some of these people took the easier assessment, the supplemental assessment. So whatever we have in our basic and below basic levels it is more homogenous group.

I would say go with the 2003 numbers and the 1992 numbers that we report are also accurate and they are based on the re-analyses of that data using the new methodology.

Dr. Sandra Baxter: Okay, thank you. There is a question here from one of our viewers. Is there research across countries in terms of the impact of literacy and health? Do countries that have universal health insurance also have the infrastructure to help low literacy patients? Do we have any international data, Sheida?

Dr. Sheida White: We don't have any international data on health literacy to my knowledge.

Dr. Sandra Baxter: Okay. Toni, a question for you. What are some of your recommendations for helping the community as a whole increase their medical literacy knowledge? So looking across the various doctors and patients for a community, what can a community do to raise health literacy levels?

Toni Cordell: Do we have another couple of hours? There are professionals in literacy who end up with those of us who are adults trying to fix the problem. I believe it is better to educate in the first place correctly than to fix the problem later on. Of course we are able to fix the problem but it is essential that early education teaches a child to reach before they exit the third grade. Now the whole community really depends on that. It is not just the problem of that student that falls behind. It is not just the problem for the parents who are dealing with that student who may – well most recently somebody has sent me some research material talking about children age boys, excuse me boys, ages 7 to 10 who were poor readers in school have a higher percentage of depression. It was indicated over and over and over. And they came up with that based on reporting back from the parent, the child and the teacher. So this wasn't an isolated case. Everybody around this young student knew this was happening.

For me, when I think about my own story, if somebody could have fixed this problem when I was in the third grade my life would have been easier. So I do believe that if we make sure the educational process is working and working correctly that we catch a child as they are falling through the cracks. I don't know how. I am not trained to be a teacher. But we have to do it right the first time. And when it is not done right the first time let's then fix it the following year or the next year. Let's not do social promotion. I'm an example of social promotion. It was probably much easier to push me through than to figure out what to do with me. Poor reading skills often add to juvenile delinquency. Why do we need that? That costs us way more than educating a child. Not just in dollars and cents but in broken hearts of moms and dads and broken lives.

So for me it is educating the child correctly in the first place. And if doctors want to get involved then let them go to the literacy programs in their community, have a sit down with some of the adult literacy students face to face, get acquainted over a cup of coffee, a sandwich, and find out that we are human beings. Again we didn't do this to ourselves on purpose. It is not because we don't want to comply. We do want to be a part of the community. And by the way, those adults like me that I have met who have gone to programs and have gotten help, we are thrilled to have the opportunity to be a part of the solution. We don't really want to be a part of the problem.

Dr. Sheida White: What programs did you – Can I ask you?

Toni Cordell: Yes you may. In 1987 I was in Oklahoma City and went into a literacy program. And they assigned a tutor who sat down and used the LABAC technique to teach me the sounds of the letters. I had never been taught phonics. And the LABAC system had an overlay of an image with each letter. And I seemed to very visual and it worked like that for me. Now I know we have some who want to argue whether phonics works or whole language. I would vote for phonics because I had had whole language and it had not worked for me. But then again, I know we can have experts on each side of the issue come and beat each other's brains out. We'll let's stop doing that and let's do whatever is necessary to educate.

Dr. Sheida White: So what you are saying is you had a high school degree?

Toni Cordell: Oh, I graduated from high school.

Dr. Sheida White: You graduated from high school but you couldn't read?

Toni Cordell: My joke is that I couldn't have read my, I still don't know if I could spell the word diploma. I'm still not a great speller.

Dr. Sheida White: You had problems with phonics.

Toni Cordell: I didn't know how to sound out the words. And a strange situation is I still can't figure out how to spell the word decide. So I have to write that in the front of my dictionary. Because I go D-E-S-D-I-S-D-E-I-C-D-E-C-E. I mean I begin to just play this horrible game and I have to look in the front of the dictionary because I don't know enough of the letters to look it up in the dictionary. Does that make sense?

Dr. Sheida White: Yes, and so what you are saying is that training the child early on with the proper basic reading skills is the key.

Dr. Sandra Baxter: Correct. Without reading how is the child going to help themselves. That has exactly been the point of federal policy over the past several years. We have really been focused on the issue of teaching children to read early.

Dr. Sheida White: And early.

Dr. Sandra Baxter: Have all students reading on grade level by grade 3. Toni we will have to keep you in mind and bring you back next month when we have our webcast on adult reading.

Toni Cordell: Alright.

Dr. Sandra Baxter: And we will talk a little bit about the component skills, appropriate instructional techniques and what really matters, what it is important to do to help adults learn how to read. You are right, there has been what has been called the Reading Wars going on for a number of years. But I would like to believe that with the National Reading Panel's report and with the work that is coming out of the National Institute for Literacy, the US Department of Education's Office of Vocation and Adult Education on adult reading that we are putting those wars to rest and really moving towards evidence-based practice.

So for our viewers we will have a webcast next month devoted entirely to that topic. We hope you will join us for that one as well.

We have just a few more minutes here. Time for maybe two more questions. Sheida could you tell us when the next Health Literacy Assessment is scheduled?

Dr. Sheida White: I don't know.

Dr. Sandra Baxter: Okay.

Dr. Sheida White: I don't know. It is not for me to decide. The higher ups have not determined that.

Dr. Sandra Baxter: Okay, so we are still waiting to hear –

Dr. Sheida White: We are still waiting; I'm sorry.

Dr. Sandra Baxter: Alright. And let's see. Give me a moment to –

Dr. Sheida White: Sure.

Dr. Sandra Baxter: With health literacy so strongly associated with English proficiency and educational levels, do you see adult and family literacy programs and with ABE, GD and ESL services playing a role in addressing this problem?

Toni Cordell: I think it is a perfect place to add every person who has a stake in the success of education. Family literacy. Are there opportunities for a medical professional to show up at a program and have an exchange, not just a lecture, don't just talk at me, but get me engaged in the discussion. Can I share some of my personal issues? And then can I ask you lots of questions? It seems to me every stakeholder needs to be brought to the table and get back to mutual respect. In the past, in my early childhood the doctor was on such a pedestal, the he, the man doctor was on such a pedestal that we didn't dare ask questions because it seemed it would be an insult to their education and intelligence. Now a patient walks in with evidently a ream of paper they have just gotten off the web and the doctor may feel horribly intimidated. I don't know.

But let everybody come to the table. And I have been very impressed at several of these organizations. The National Patient Safety Foundation inviting me to sit on their board of governors, not because I have an education but

because I am thinking about this issue from my perspective. And my perspective has value.

Dr. Sandra Baxter: And I think that is a really important point to keep in mind. Keeping the lines of communications open between the various communities that have a stake in this issue really is what is going to lead to a resolution of the problem or strategies appropriate for addressing it.

We have received many more questions than we have an opportunity to answer right now during this live webcast. But we do plan to take those questions and we will answer them and post the questions and the responses online at the Institute's website at www.nifl.gov. I want to thank my wonderful panelists, Dr. Sheida White, Toni Cordell for being with us today. And I want to thank you the viewing office, the viewing audience for taking time out of your busy schedule and joining us for this important dialogue.

We do believe that the results of the National Assessment of Adult Literacy, the viewpoints expressed here, and viewpoints expressed by other experts around the country are going to make a difference in addressing this critical issue in our community and in our nation.

Remember, you can view this webcast again at the Institute's website. It will be archived and saved there for you. For the National Institute for Literacy, I am pleased to have been a part of this dialogue and we encourage you to share your questions, comments and ideas with us on the Institute's discussion list. Thank you so very much for joining us today. From Washington, DC, this is Sandra Baxter.