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2018 EHDI Annual Meeting

EFFECTS OF EARLY HEARING DETECTION AND INTERVENTION ON LANGUAGE DEVELOPMENT IN CHILDREN WITH HEARING LOSS AT 14 AND 30 MONTHS OF AGE

Topical Session 6

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>> ASHLEY: Can you hear me? Okay. Hi, I'm Ashley, your room monitor. Everyone should have eval forms on their seat. If you're missing one, I have more in the back and you can just leave it on the back table when you go out and we'll go ahead and get the presentation started. Thank you, everyone.

>> ELIZABETH SEELIGER: Good afternoon, everybody. Thanks for coming after lunch. Hopefully this will be an exciting enough presentation to keep you awake and engaged. We have some fun things to share with you. I'm Elizabeth Seeliger, the Program Director of the Wisconsin Sound Beginnings program. And Christi Hess and Anne Harris are also here today, and they'll tell you more about their role and agency when they come up and talk.

Okay, so the presentation objectives today are the same as what was listed in your abstract. So I'm not going to necessarily read these. But I'm going to tell you how our presentation is organized today.

So we'll give you a little bit of background about how Wisconsin is doing as far as meeting our 1‑3‑6 goals, so what is the state of the state as far as EHDI is concerned in the state of Wisconsin? We'll give you background and history of our research project and agency collaboration and how that's informed what it is we're looking at together.

AEIOU stands for: Assessment of Early Intervention outcomes. So it's our assessment of Early Intervention outcomes research study so we'll go into the methodologies and details of that study and some of the clinical and programmatic implications in our state and beyond.

So some of this data will look reflective of your data but before we get started with that can I see a raise of hand of how many of you are state EHDI Program Coordinators like myself? So it will probably look familiar to people like you. How many of you are audiologists?

Great. Early Intervention, speech‑language pathologists?

How about parents? How many parents do we have in the room? Okay, perfect. Physicians or other professionals?

Did I miss anybody? Researchers?

Kind of? Okay, good. Great. How about students? Yay! Okay.

[ Laughter ]

All right, excellent. So like in many of the states, Wisconsin is doing a very good job of screening babies and we're doing a very good job of screening babies by one month of age. We've been pretty consistent around this 99% level for many, many years now.

In Wisconsin, our percentage of kids who are diagnosed by 3 months of age as deaf or hard of hearing is right around 55%, and has been pretty consistent, around 55%, for many years. We had bang‑up year in 2016 by increasing it by 3 whole percent. We're working hard on getting kids earlier identified, but we have a pretty strict criteria for what diagnosed means, the final confirmatory diagnosis, so not just, "We have some suspicion that there might be a hearing loss," but we know the degree and configuration of that hearing loss. That's when they start reporting it to the state EHDI Program, so some of these kids are sort of in diagnostic process for quite a while and we don't take the first diagnostic evaluation. We take the last one. Does that make sense?

Okay, so and then unfortunately, only 37% of our kids are enrolled by 6 months of age. We have closer to 78% of our kids who are enrolled at any time in Early Intervention services but when we looked at the strict definition of kids enrolled by 6 months of age, that weren't enrolled because they had a different diagnosis, so if they were enrolled because they were significantly premature, or they're enrolled in Birth to 3 for some other reason, we didn't include those. We only include the kids that were identified and enrolled because of their hearing loss where we can make a difference in our EHDI Program. So those kids, 37% of babies are enrolled by 6 months of age. The reason this matters when we're looking at our research study is because the kids who meet our 1‑3‑6 criteria, their families are the majority of the families who also enroll in our research study. Okay?

So it's a sub‑portion of the overall total population.

How do we know all of this data? So in the state of Wisconsin, we have a home‑grown data collection and tracking system. It's a web based tracking system. And it is fed into our system through the metabolic screening card program, and connected to our Vital Records Data System. So we have an over 98% match criteria between our screening database and Vital Records so we know we're screening all the current births and they're updating that in our Data System. We have 100% of our audiologists submitting data to the WeTrack system, and we have an electronic referral mechanism to our Part C Birth to 3 program, so we know that all of our kids are also being referred to Part C Early Intervention.

Our we track Data System is our public health safety net. We need to make sure families are getting timely and appropriate follow‑up services and acts as the safety net to help us know which families we need to target special interventions for, and what it does not do currently is although we collect on every child identified as deaf or hard of hearing referral information, as well as enrollment and unenrollment information, and referral to Part B services so we also collect whether they're referred at the end of their Birth to 3 years to our school system, and eligibility for Part B systems. We don't get any sort of developmental language outcomes in our Part C sort of data set.

So what we can say is that kids are referred, that they're enrolled, that they stay or don't stay enrolled but we don't actually know whether or not kids are making developmental progress in Early Intervention. So that was kind of the impetus behind looking at this developmental research study. So that's the background and history.

And I'm going to turn it over to Anne to talk about the plan.

>> ANNE HARRIS: So we just heard from Elizabeth about what's happening in Wisconsin. And I'm going to give you a little bit of background, history and a little description of our collaborative nature of our project. And then Christi will go into some of the research results.

So just a little context: Again, Elizabeth described what information we do have, but we also are very interested in outcomes for the kids going through this process, and we've had a lot of great partners. In fact, one of the impetuses for our original AEIOU study was the NECAP study, which is the National Early Childhood Assessment Project. And we'll talk a little bit more about that. They've had many publications and some recent publications where they've shown that children identified with hearing loss before 3 months and receiving intervention by 6 months of age had a higher verbal quotient, and this was one of our assessment tools, but the NECAP study in general had many assessment tools, and this was just one result that they reported on.

Another sort of contextual piece of background is that there's another group doing some research on looking at language outcomes in children and they've been comparing those with the nonverbal IQ, and coming up with a different kind of a quotient, and they've demonstrated that language underperformance continues to be a problem for children who are ‑‑ with hearing loss over the time period that they studied which was under 6 years of age.

So these ‑‑ they do have some longitudinal data and I've heard some reported at this conference which is great but these particular reports were done on cross‑sectional studies, and have suggested that we need to do more longitude y'all work to look at outcomes for language ‑‑ language development in these children.

So I'm going to talk a little bit more about our partnership, and just the three of us, I'm a public health program evaluator. Christi Hess is a speech‑language pathologist. Elizabeth Seeliger is an audiologist so we represent an interdisciplinary team and we also come from different perspectives where we work. Elizabeth introduced herself as the Director for the Sound Beginnings program which is our state EHDI Program.

They WSB partners with several agencies in the state to implement the program, and one of those partners is our University of Wisconsin‑Madison Waisman Center, University Center for Excellence in Developmental Disabilities, or UCEDD and that's where I work. I'm the LEND Director, as well as have a number of research and program projects with the State Title V Children and Youth With Special Needs program, and then we also have some outreach specialists in some of the local Health Departments to do some more of our screening and follow‑up with the Sound Beginnings program.

And then finally we were one of the states that participated in the University of Colorado's NECAP study, so all of these people contributed to this research, and the Assessment of Early Intervention Outcomes study in Wisconsin was started as the initial partnership between the UCEDD, the Sound Beginnings program, and the NECAP project, starting in 2009, so we started on a very small level collecting data there. Christi's going to tell you more about the actual measures and some of the assessment that we did but we recruited families, and our recruiter I think is maybe here or is certainly at the conference.

But children who were identified with a diagnosed hearing loss in Wisconsin were contacted, their parents were contacted at 13 to 14 months of age and offered the opportunity to enroll in our study. And it was IRB approved at UW Madison.

They completed these assessments when they were first enrolled, and then again when the children were about 30 months of age.

The assessments that were part of the NECAP study, we did send to Colorado for coding and they sent us back reports, and also reports for the families that were participating, and then in Wisconsin, we also had some additional measures related to social‑emotional development and a couple of other sort of corroborating measures. We're not going to report on some of those but just to let you know we did collect some additional data.

And then in 2016, we got some additional funding, I mentioned here, through the Disability Research and Dissemination Center, it's actually CDC funds, on a Cooperative Agreement, to expand the AEIOU study so reenhanced our recruitment. We supported some different approaches to Early Intervention in the state and we started to do some more in‑depth data analyses so we were able to really build on something that the Sound Beginnings program had started in kind of a small way, and sort of blow it up a little bigger, so that's why we're excited to share some of our first analyses with you today.

So on a broad level, our first question was: What is the impact of receiving Early Intervention on developmental outcomes, and specifically what we'll be reporting today are language outcomes, for children with hearing loss, as measured at these two points in time? So that was sort of the broad AEIOU research question.

And then specifically, with this EHDI outcomes additional funding we wanted to look at: Are there differences in developmental outcomes for children who are identified by 3 months of age, and/or enrolled in Early Intervention by 6 months of age? So that's some of the results we'll be sharing with you today.

>> Thanks. So you are stuck with me for the nitty gritty details of the research study. We learned what's happening in Wisconsin. How overall we're doing as a state meeting the 1‑3‑6 model. Anne described the background and collaboration between the Waisman Center and Wisconsin Sound Beginnings, and our partnership and the history of this project. And now I'm going to go really in‑depth into our research study, explain the eligibility criteria and our results.

So in order to be eligible to participate in AEIOU, children could have unilateral or bilateral hearing loss. Their hearing loss had to be permanent, but it could be conductive or sensorineural in nature.

Any degree of hearing loss was eligible, so mild all the way up ‑‑ slight, mild, all the way up to profound.

We enrolled children with hearing loss only and with hearing loss and additional disabilities. English, Spanish, or American Sign Language as the native language, primary language, at home.

And for the first 7 years of our research study, the children had to be enrolled in Part C intervention, so in our state's birth to three program. We later changed that when we got that additional funding that Anne mentioned, but to keep things clean, we're only presenting on the children that were enrolled in Early Intervention today, because we only have a small handful of data from children not in Birth to 3. So there's a little caveat there but for all intents and purposes, all the kids we're talking about today were enrolled in Part C Early Intervention.

So those were the eligibility criteria and this is the demographics of who we got. So who enrolled. We're going to talk about Phase I to start. I was thinking maybe ‑‑ oh, it is a pointer.

So for our Phase I, which is the 14‑month time period, we have 116 children to date, and you can see here, the average age is 14.6 months. We have a range of ages when they actually got us the packet and mailed back the test forms.

About a 50/50 split of males and females. Maternal education, there's a range from 8 to 19 years. This is one of the areas where we're different than the NECAP study. Our group of participants has a relatively high maternal education, so we'll take that into consideration later when we're talking about our results.

We have about a quarter and ‑‑ so 1/4 with unilateral hearing loss, and about 3/4 with bilateral hearing loss, and then you can see here the breakdowns of slight to mild, moderate to severe, severe to profound, and then currently, it says we have about 1/3 with unknown or missing data in terms of degree of hearing loss. Because we're sharing data with NECAP, we have pretty stringent coding requirements to categorize degree of hearing loss, and so we're working to fill in some of our missing data.

We have about half of these, 15, they're just not coded yet so those will eventually get added in. But we did have some missing data. And then about 1/4 of the population had additional disabilities. And so those are the kiddos who participated at Phase I. To date, we have about half of them who have finished Phase II. So at Phase II, we have some attrition, so some families choose not to participate in the second phase. And then we have a handful of children who are just not old enough yet. So we wouldn't be able to tell you their results because they're not 30 months yet. So it's a combination of both. Some families move, and we can't find them at Phase II, as well.

And overall, I would say the means and averages are fairly similar. We're pretty confident today that when we're talking about looking at Phase I versus Phase II, that it's a similar representative group that completed Phase II.

Any questions on the demographics?

Okay, so today we're going to be talking about two outcome measures. NECAP, like we said, is a full assessment battery. There are many measures. Today we're going to talk about two, in particular. So the first one we're going to talk about is the MacArthur‑Bates Communication Development Inventory. It's a parent and report questionnaire. So I just hinted at filling out a packet. That is how our assessment is completed. We call the families to recruit them. If they agree to participate in the study they're mailed a packet of parent questionnaires, and they complete them on their own and then mail them back to us.

The MacArthur‑Bates measures receptive vocabulary, expressive vocabulary, gestures, and grammatical markers and then there's a vocabulary inventory for words understood, words signed, words spoken and gestures uses. How many people have seen the MacArthur‑Bates before? So you're filling in bubbles word by word based on the kiddo's age and functioning.

And then we're also going to report today on the Minnesota Child Development Inventory. Again, that's another parent questionnaire, and we get scores for social development, self‑help skills, gross motor, fine motor, language. It breaks apart receptive. Nonverbal skills, understanding and interaction with the environment. That is a more broad measure across multiple domains.

So we are going to share today quotient scores, which are not the exact standard scores from the test but we're using the kiddos' chronological age and multiplying it by 100 to get a quotient score. That's what Colorado does, as well, and so they're helping us with the coding, and giving us these quotient scores with the NECAP data.

So for our first set of results, we're going to talk about the group as a whole. So like I mentioned, we had 116 participants at Phase I, and 62 participants at Phase II. So right now, we're going to talk about results for all of those kiddos grouped together, everybody that's participated in Wisconsin to date.

And just a little bit more about who is in this group: We wanted to look at how many of these kiddos were meeting ‑‑ were being identified by 3 months of age. So as a group, the age of identification mean, or middle, is 3.3 months. And at Phase II it's 3.2 months. So like Elizabeth hinted at, we know that this is a bit of a self‑selected group to participate in our research, and it doesn't exactly match how our state's doing so we know our state average is not 3 months of age for identification but for this research study and these 116 kiddos, that was the mean.

And then average age of intervention is below 6 months. So 4.9 months at Phase I and 5.5 months at Phase II.

So what we're going to do now is walk through the results of this study. The next handful of slides are all going to look fairly similar so I'm going to explain sort of the axes to you and we'll look at the results. The first set of results is the results from Phase I. So that's the 116 kids, and we broke them into two groups: Those who met who were diagnosed by 3 months and those who were diagnosed after 3 months. And then we're looking at all of these different outcome measures to see how those two groups are doing.

So on all of these graphs the MacArthur‑Bates is going to be first, and then the Minnesota scores broken into those different domains are listed next so we have Minnesota expressive language, Minnesota receptive language, SE stands for the social‑emotional quotient and then the Minnesota also gives us a cognitive quotient. And then we can check out their quotient scores along the Y axis, anywhere from 80 to 120 is considered within the normal range so again looking at this before 3 months and after 3 months for the whole population, 116 kids, we had 72 identified before 3 months and 43 identified after 3 months. And here you can see the means for each group so the blue group is those identified before 3 months, and the orange group is those identified after three months. The standard deviation bars are those black bars so they're telling us there's a lot of variability and then these are the results for the rest of them.

So when there is a significant difference between the groups, I have a star above the two bars. For this particular result, there's no significant differences at Phase I, looking at whether they were identified before or after 3 months. So we're sort of going to march through these and then we're going to go back and do some wonderings about why our results are the way they are.

So the next thing we did was break the same group differently, into those who were enrolled in Early Intervention before 6 months, and those who were enrolled in Early Intervention after 6 months. The split is fairly similar, 71 and 33. We're looking at the same thing, same ideas.

So here you can see the MacArthur‑Bates scores and here are the rest of the scores. Want to take a minute to point out, these kids are around 14 months of age when they're completing this and almost all of the means, the MacArthur‑Bates being pretty much the only difference, everybody's mean is within normal limits. Until the plenary talk this morning, we were feeling comfortable, feeling pretty good about that. But after this morning, maybe not being at 100 should be thought about differently. So we'll take that into account in how we're sharing our data.

But the means are within normal limits at 14 months for this group of kiddos. We also know that the kids with additional disabilities are included in this group, and the kiddos ‑‑ so some of those have cognitive impairment, so they're still in this group.

So then we looked at the kiddos who met both, again, so here again there were no significant differences between the two groups. So we thought maybe we should look at those who met both 3 and 6, and those who didn't meet 3, didn't meet 6, or didn't meet 3 or 6. So you had to meet both to be in the one group. If you met neither one nor the other, or none of them, you were in the second group.

Here, our split is closer to 50/50, because it's a bit more stringent to meet both. The MacArthur‑Bates results look very similar to how they've looked with 3 and 6 separately. And again, all of the Minnesota quotients look similar, with no significant differences between the groups.

I see some worried faces.

So then what we did was we looked at that same group at Phase II. So now we're just talking about the 62 kids that have finished Phase II. Everybody who's finished Phase II to date. They're 30 months old at this point. Yes, thank you.

So before 3 months we have 39. At or after 3 months, we have 23 kiddos. And this is the same meeting the 3‑month guideline broken apart. So MacArthur‑Bates scores are lower at Phase II. The means are no longer close to within that normal range.

And for the first time, we're seeing some significant differences between the groups, so it's popping out that the kiddos who were diagnosed before 3 months were doing significantly better in both the expressive language quotient area and in their social‑emotional area of development at 3 months.

If you can sort of picture in your head the Phase I results, all of the bars are lower at Phase II across the board, so comparing 14 to 30 months, we'll go into that in a second, but everybody's not doing as well ‑‑ don't want to be super‑negative ‑‑ at Phase II.

So again we split the group to those who were enrolled before 6 months and those who were enrolled at or after 6 months. And there were no significant differences between the groups.

We did the same thing, so we looked at those who met both 3 and 6, and those who didn't meet 3 and 6. Again, we're fairly confident that we're sampling the same group of kiddos that have completed Phase II. People are really upset by our results.

[ Laughter ]

There were no, again, no significant findings at meeting 3 and 6, or not meeting them.

So this is sort of a summary slide looking at Phase I versus Phase II. So what we wanted to do next was sort of look at a longitudinal track. We had separated out what did they do at Phase I, what did they do at Phase II, and we wanted to look at them together, that Phase I versus Phase II comparison. So on this slide we just have the 62 children who completed Phase I and Phase II shown, so this blue line is only the children who completed Phase I and Phase II. It's not the whole Phase I group of 119 kids. These are the exact same kiddos in the two lines. So this is sort of the summary of what we saw on all the previous graphs.

Anybody want to guess where the Phase II line is? Yeah.

So these are the Phase II results. I couldn't put the standard deviation bars in there, because they overlap, so you wouldn't be able to see them. They're all significantly different, and lower, at Phase II. This is not a new finding. It's consistent with what Colorado is seeing across the board. So 14 months is in blue, and 30 months is in red.

What we wanted to look at next was a subset of the full sample that we have. So for the next set of slides, we're going to be talking about a subset of our data. We're going to be talking about the kiddos with bilateral hearing loss and no additional disabilities. That is what Colorado's most recent publication looked at, and found some important findings with meeting 3 and 6, so we were trying to see if our data would replicate, and show the same thing.

So when we take out the kiddos with unilateral hearing loss and take out the children with additional disabilities, we have about half of our group, so we had 116, and we remove unilateral and we remove kiddos with additional disabilities and we're left with 66 children.

The means are still close to that 14 and 30 months. So we have 66 children who have completed Phase I, and 33 children who have completed Phase II.

Our age of identification looked similar for this group, so they're as a group meeting the 3 months. Again, the range is really wide, so half a month, 2 weeks, I guess is fair to say, all the way up to 16 months or 15 months. And then age of intervention is below 6 months for this group, as well. 4.4 and 5 months.

So another thing to take into consideration as we start talking about these Phase II results is our N is starting to get pretty small. We're only talking about 33 of the kids out of this 116 that we have results for.

So again, these are the kiddos with bilateral hearing loss and no additional disability that we're talking about now, so we separated out those kids, and we were looking at meeting 3 months. And again, the means are actually a little bit higher than they were when we were looking at that first group, and I think that makes sense, if we think about taking out the kiddos with additional disabilities. We weren't sure what it was going to look like because we thought maybe the unilateral kids were doing better language‑wise and we were taking out the ones with additional disabilities so we might meet somewhere in the middle, but at 14 months, I think the unilateral and bilateral wasn't showing a lot of difference so the means are higher in this group.

When we look at Phase I, so again the 14 month olds enrolled in Early Intervention by 6 months or not enrolled in Early Intervention by 6 months, we found some significant findings that for this subset of our overall population, so just the kids with bilateral hearing loss and no additional disabilities, it looks lake even at 14 months ‑‑ so this is pretty early. They haven't had a lot of time to be enrolled in Early Intervention, if you're thinking about they were enrolled by 3, 4, 5, 6 months as our mean, and we're testing them by 4 months, so they probably haven't been enrolled very long, but the kiddos enrolled before 6 months were doing significantly better across the expressive language, receptive language, and social‑emotional means of the Minnesota.

I know it's a lot of data so I'm trying to go slow so that your brains have time to process all of the different slides with information.

Again, we split the group into meeting 3 and 6, or not. And there were no different findings here. So the means are looking similar across meets 3, or 6, or meets 3 and 6, there's not a lot of bouncing around and there's significant differences. We're close to that 50/50 split when we're talking about meeting both 3 and 6.

So here's where our N starts to get really small. We're talking about those 33 kiddos who have completed Phase II, who bilateral hearing loss and no additional disabilities.

So 21 of them were diagnosed before 3 months, and 11 were diagnosed at or after 3 months. It's the same proportions that we have throughout meeting 3 and 6, again, we have significant findings for the expressive language quotient and the social‑emotional quotient. So interestingly, at Phase II, this is popping out that meeting the 3 ‑‑ I want to be careful in my wording ‑‑ is significantly ‑‑ is predicting significantly better results for the expressive language quotient on the Minnesota, not on the MacArthur‑Bates.

Meeting the 6 month guideline, there's no significant differences between the groups, so this was really interesting to us. If you remember, at Phase I, we were showing a difference across expressive, receptive, and social‑emotional language for this cohort. When we tested those same kids again at 30 months, there was no effect of being in an Early Intervention by 6 months. Again, we'll do some wonderings about that in a minute. Like, how that got washed out over time.

We don't have the answers. We're just going to wonder with you, after we go through the results.

And then as our last, like, big results slide, we looked at that 3 and 6 again, and there are no significant differences for meeting both 3 and 6, for these group of kiddos with bilateral and no additional disabilities.

Interestingly, the longitudinal trajectory looks a little bit different for this group. Again, that sort of makes sense to me when we're taking out the kiddos with additional disabilities. So they're still doing worse at Phase II, not as well, but if you notice, those means are higher, and as a group, they're sort of staying within that 80 to 120 range at 30 months.

Here you can see the social‑emotional and the cognitive. Again, this is making sense to me, that we're taking out kiddos with additional disabilities so the cognitive quotient is fairly stable, when we're retesting the same kids. Social‑emotional is staying pretty well. Expressive language dips but not super dramatically. Same as the MacArthur‑Bates here. There's a little bit bigger of a gap, but none of these are significantly different, so we can't say much about that.

So in terms of our wonderings, again we have this group of 32 children who have bilateral hearing loss and no additional disabilities, and we're sort of wondering what's happening. So we were wondering, now we have 32 children, we're wondering who these kids are. We're starting to wonder what their Early Intervention looks like. We can dive a little deeper because it's only 32 children.

So we've just started to do some longitudinal analysis, and I'm going to describe the way we're doing it, with a statistician so I'm not going to describe it in too much detail. That is not my role. But we do have some preliminary results. So we started looking at individual trajectories. So this is a little bit messy, because there are 32 individual lines. And I don't really want anybody to have to interpret this or take anything away from this, other than we know exactly which kids start where at Phase I, and we can look at which kids are where at Phase II.

And this is the results from the expressive language quotient. I just graphed this one because that was one of the significant findings with differences. So for example, there's this kiddo who ‑‑ let's look at this dark blue line ‑‑ was around 90. I'm just making a guess. And then at Phase II was doing, like, off the charts well above one standard deviation above the mean at Phase II and then there's these other kiddos who were doing well who dipped really low. These are just the kiddos with bilateral hearing loss with no additional disabilities, remember.

So what we're going to do in our analysis now preliminarily and in the future is look at these change scores to think about who these kids are that are doing different things, and wondering if they fit into different groups. So we have a group of kiddos who have a positive change score. So they improved from Phase I to Phase II.

And the slope of the positive can be different for any child, so it could start down here and go way up, or it could just be a small positive gain.

We have some children with a negative change score. So they were doing one place at Phase I and they got worse, or had a lower score at Phase II.

And then we have some who didn't change much, and stayed stable. So there are some statistical analyses we can do, where each child only has one score instead of looking at their two separate scores, and we're just looking at their change score over time. And that's what we're going to start to do. Again, we have a pretty small N so we'll start to look at that to pull apart these kiddos to see if they fit into any different groups.

This probably isn't surprising but again, most of the children had negative change scores. So almost everybody is decreasing their score at Phase II.

However, when we look at that Minnesota expressive language quotient, again, so this is now the third time that Minnesota expressive language quotient is showing us something significant. We were able to control for maternal education and the degree of hearing loss, and the Minnesota expressive language quotient was a significant predicter ‑‑ I said that wrong ‑‑ being identified before 3 months was a significant predicter, like, you were more likely to have a positive change score on the Minnesota expressive language quotient if you were identified before 3 months.

Again, we're going to continue to look at these longitudinal results and as we get more Phase II results back, hopefully we can say more about these things.

So we have hit those three points. And now we're going to talk about some clinical and programmatic implications. This is where we're doing a lot of wondering about what our results are saying, and what they mean.

So clinically, we know that Wisconsin has non‑categorical Birth to 3, which means that not every County ‑‑ each County has their own Birth to 3 program, and not every County necessarily has a specialist on their team. And so we have parent demographic forms that parents have filled out as part of this battery that describes the services that their child is getting or was getting or got, depending on when they filled it out, so we know what type of intervention they were getting and we know the frequency that they were getting intervention, so we're going to do a deeper dive into that piece of our demographic form to look at the potential implications of that.

On a systems level, Elizabeth described our we track system and how we can use that to look at whether or not children stayed enrolled in Early Intervention, so again, when these kiddos completed this assessment battery, they were enrolled in Birth to 3. It doesn't necessarily mean that they didn't drop out in between 14 and 30 months. We don't know what happened after 30 months with these kids.

And then statewide, we want to continue to support Early Intervention programs to provide these services, as our EHDI Program in Wisconsin. So again, looking at that enrollment piece, though, systems‑wise, like we said, we have that data in our we track system so we can look at the number of kiddos that stayed enrolled versus the number of kiddos that dropped out and so we've just started to do that. We have a lot of data and this we're trying to figure out how it fits where.

So this is one year's worth of data. I think these are all the children born in 2016, again it doesn't match up with what we're talked about with our AEIOU results, but this is where our collaboration is really important, and we can pull different pieces in from different data systems to try to make sense of our results. So every year, we have ‑‑ this is, like, 150, 162 kids ‑‑ that we're looking at data for, and we can look at whether or not they were enrolled in Early Intervention before 6 months, and enrolled in Early Intervention after 6 months, and the likelihood that they completed the program.

So this was not intuitive to us. We were surprised by this finding, that if you enrolled by 6 months, only 65% of the kiddos completed Early Intervention, or stayed enrolled until they were 3.

Maybe it's a good thing. Right? Like, we don't know why they weren't enrolled, so maybe, I don't know, they met their goals. I have feelings about that, but they didn't stay enrolled until they were 3. Whereas, if they waited until after 6 months to enroll, 79% of them completed and stayed enrolled until they were 3. This is sort of the opposite of this. But just so you can see it. And then there's some that we don't have data for, which is a really small percentage.

So we're starting to look at our Early Intervention data to wonder what's happening with our Part C Early Intervention.

I think we've hit all the four points, but we wanted to spend some time talking about some conclusions. I've mentioned some future directions. And we are hoping for some question time and input.

>> Okay, so just to ‑‑ we thought we'd go back to our original objectives for today, and the first one was just to have you and us understand the demographic variables of our study population. Keep in mind this is a group of Wisconsin children at two time points all of whom the data we were reporting today were receiving Early Intervention at the time of enrollment and about 50% of those kids were diagnosed by 3 months of age, and enrolled by 6 months of age.

We also wanted to describe what we were finding, and again, based on what Christi presented, most of the assessments that we completed, the children were performing in what you would call a typically developing range, between 80 and 120 on those slides that you saw at 14 months of age. There were some different trajectories as she described apparent by 30 months of age and we're going to explore those a little bit more ‑‑ a lot more.

The only significant predicter that we found was a better expressive language quotient when the child had been identified as having hearing loss before 3 months of age. So that's the only thing that we're pulling out of that array of slides that she presented.

And what we're really thinking at this point is that we need to know more about the Early Intervention services to interpret our results. Again, we're talking about how to look at what the children are getting, and whether they stayed enrolled, and whether some children actually went in and out of enrollment a couple of different times, so what were they actually getting during this time period?

In terms of future directions, we are going to continue to analyze our data, and we have several publications that we're thinking about pursuing. We do want to pull in some of that social‑emotional data, again some of the things looked like there were some trends around significance, and we also wanted to look at some of the other types of Early Intervention that we've been doing since then, and get a better sense of what those different types of collaborations we've had between the EHDI Program and our Part C program could do. That's the model of service delivery.

And then we're also going to look at sort of the intensity, so how much is enough? Or were those different trajectories getting different amounts of Early Intervention?

Sure.

>> As we go in future directions as the state EHDI Program I took away an additional clinical implication for that. Way back at the beginning you saw we only get about 50% of our kids diagnosed by 3 months of age. The significance of the implication that that's the only thing that's popping out as a predicter of expressive language scores gives me some power in talking with my audiology colleagues about why we need to continue to work super‑hard on getting kids diagnosed by 3 months. So that was kind of exciting to me as an EHDI person. The other thing I want to pop out, if you remember at the very beginning of the study, the parents who submitted the assessment results back to us had a very high maternal education score. The packet is all parent completion.

The assessments are not small, and it takes some significant dedication I think to fill them out, and I think that contributes to who our study population is. I think it could also potentially ‑‑ this is all just hypothesis ‑‑ contribute to how many of our kids are in that typical standard deviation, typical range of development for these assessment scores. If you look at the pediatrics publication by Colorado, maternal education is a predicter of developmental outcomes for kids who are deaf or hard of hearing so I think that might also be inflating our scores just a little bit, so just wanted to add that.

>> Thank you. That's part of the fun of the interdisciplinary and different programmatic perspectives that we have on our team.

So we're also looking at we actually have started in the last year a Phase III, which is reenrolling and children at about age 60 months of age, and we're looking at the same tools, if it's still age appropriate, because some of them are normed on certain ages, so they're going to complete all of the same assessments. And then we're also doing direct assessments by Christi and our co‑collaborator, who is Kayla Kristensen. She was listed in our ‑‑ as one of the presenters here, but she's not here at EHDI this year.

And we're actually looking at comparing the parent and direct assessments to see if they match up, and looks like they are pretty close.

And then we're also going to look at constructing developmental trajectories. There's some different ways to do that statistically, and we're getting some expert advice on really sort of how to look at those patterns of development. We'll be able to then add that third point in time, so we're excited about that.

So I just wanted to thank our study team and collaborators. The first two are EHDI employees, as well as working on the research. Connie Stevens and Rebecca Martin. We have our LEND and UCEDD Trainees and support staff. We've been collaborating for years with Allison Sedey and Christine Yoshinaga‑Itano, at the University of Colorado. We also had a couple of people involved at the very beginning. That's why we have this additional social‑emotional data. We have several very interesting and validated measures that were developed by Roseanne Clark and Linda Tuchman‑Ginsberg, and they're going to look at this data. We have video data of this kids and we'll be coding and see if that relates in any way to some of these developmental trajectories.

So those are sort of exciting new directions and just acknowledge the partnerships that we've already told you about, especially the families that have participated in the research.

So I don't know if you have a questions slide but that's it for our video presentation but we can go back to anything, if you want, as we field questions, or if you have anything you want to talk about.

Yes?

[ Off Microphone ]

>> So I was at an Early Intervention discussion earlier, and they were just talking about the disparity across districts, across states, regarding how Early Intervention services are delivered. And I'm just wondering how ‑‑ you had mentioned it on one of the slides ‑‑ if you're tracking, like, frequency of services, what sorts of modules they're using, if they have a curriculum that they're using. Is any of that part of what you're looking for as far as outcomes?

>> Testing. There we go. I have a two part answer. One is on the demographic forms we're collecting as part of the study we look at frequency and intensity and service provider type, who it is that's providing the service, and the County, so we have a County‑based system so we're looking at the County and what we know about those counties.

So we will be looking more into that. We also developed a specialized model of service delivery, where Christi, who is a Ph.D., SLP, who specializes in kids who are deaf or hard of hearing, who's also a researcher but on her other day job, she actually sits on the IFSP team of every child in a particular County, and provides sort of coaching to the providers, the non‑categorical providers, and occasionally the family is together so provides that sort of specialized knowledge and skill delivery in that region, and we're interested in looking at whether or not that's making a significant difference, as well.

So because our N size is pretty small and then you take that and then put it only in one County, we know for sure it's making a difference in enrollment. We know for sure that it's making a difference in family satisfaction of services but whether it's actually impacting developmental outcome we need more data to say anything and feel strong around that.

>> Hi. I'm not great with statistics, so I'm not sure that I fully understood some of this, but I had a question about, I this I in the beginning that when you were talking about the two populations of kids, whether they were at 3 months and at 6 months, I think you also said the average identification and enrollment was at 3 and 6 so I was wondering if you were also able to quantify to what degree the difference was between the two teams. For example, if one kid was identified at 2.5 months, he would be in one group, and another kid was identified at 3.5 months, and therefore would be in the other group, that's only a one‑month variable. Does that make sense? I guess I'm just wondering how different are the two groups? Or was that even measured?

>> I can talk about that a little bit. So the bins that we are doing this analysis by are maybe not the most ideal way to do this analysis. Like, it might be nicer to look at the distribution and make two different distributions but because of our funding and looking at the impact for JCIH we sort of stuck to those prescribed bins. When we go ahead and publish this data, we'll say more about the distributions of those two groups, and what they look like.

There is a clustering around 3 months. I would say 2 to 4 months is our big guest cluster, so they might not be as different ‑‑ it's a super relevant question. They might not be as different as we're thinking they would be but we're using that 3 months because of the JCIH guidelines. Does that answer your question?

Yeah.

>> Thanks. This is very interesting. So looking at the Phase I overall that there were no I guess statistical differences between the groups, but then Phase II was not looking as rosy, how much have you considered I'm sure you have, possibly the sensitivity of like the MacArthur at that age being they're mostly around 14 months so the expectation for words produced is largely variable in typically developing kids already. Do you think that has something to do with it and potentially are there raw scores or subtests within MacArthur‑Bates that might be more sensitive to that?

>> Yes to all of that.

[ Laughter ]

Again, really, like, we're just starting to delve into it. Colorado has shown significance with the MacArthur‑Bates and has found it is probably the most sensitive measure in the battery that NECAP uses which is why their most recent article only talked about the MacArthur‑Bates so that one in particular we feel is really representative. You notice the means are lower across the board for the MacArthur‑Bates versus the Minnesota, so we feel pretty comfortable with that one. Again, we've been collaborating with Colorado about these results.

The other ones we're continuing to explore. We're looking at sensitivity. Some of our social‑emotional scores across different groups. We're going to go back and do, like, an item analysis because the Minnesota is a more general questionnaire, and so we don't want language to be impacting social‑emotional scores so we're going to look at some of those things to try to tease them apart.

>> The state EHDI person, at some point, we're going to want to help our Early Intervention programs know which assessment tools are the most sensitive, because this is taxing for families to have to fill out this huge battery, and so as a state EHDI person, one of the things that I'm getting out of this collaboration is some information about going forward if I'm going to be asking for every 6 months a developmental outcomes assessment, what are the ones that are going to show us that there's concern first? So that we can be doing something different or better to support those kids. I'm not super interested in the ones who look really good all the time regardless of who the kid is, right? Because that's not going to help us catch those deficits early and give them additional supports when they need it.

So I'm really interested in their deeper dive of these different assessments, because it will inform our state best practices recommendations to those Part C programs.

>> Anyone else?

>> Do we know anything about the language environment of these kids?

>> Yes. I meant to say that. I thought about it while I sat down. So we only have one Spanish‑speaking family in this cohort, which again is very different from Colorado. And we have a handful, I want to say 5 to 7, kiddos who are using ASL first. So the majority are English as a spoken language.

We also have on the parent demographic form sort of a percentage ranking of a total communication, like, do you use sign with spoken language? Mostly sign? Mostly spoken language? So at 14 months that pops out more, because a lot of parents, we're talking about normal language development at 14 months, a lot of parents are combining spoken language and sign so we do have that data. We're going to pull that in, as well.

>> [ inaudible ] one quick statistical comment too. In the Phase II results, you were finding significant differences between those who met 3 months and those who didn't, did you do any correction for unequal variances?

>> So we did. They're actually non‑parametric so it's a bootstrapping test. There you go, that's my answer to that question.

[ Laughter ]

Please don't ask more.

Thank you.

[ Applause ]

[ End of session ]

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