



**Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference
November 5, 2002**

Topic: Data Linking Systems

TO: Ad Hoc Group for EHD
FROM: June Holstrum, Krista Biernath
SUBJECT: Conference call-in number and agenda.
DATE: November 5, 2002

The next EHD teleconference will be on Tuesday, **November 5, 2002** from 2:00 to 3:00 pm **Eastern** time. To join in, call: **1-800-713-1971**. You will be greeted by an automated voice and asked to enter a CONFERENCE CODE. Dial **Code 886182**. Federal participants may call **404-639-4100**. Please call in 5 - 10 minutes before the conference starts so we can begin promptly at two. If you have any questions please contact Marcia Victor (MVictor@cdc.gov / 770-488-7721) or Marcus Gaffney (Mgaffney@cdc.gov / 770-488-3504)

An internet based captioning service will be available at no charge during this teleconference. If you would like further information or to schedule use of this caption service, please inform Marcus Gaffney (Mgaffney@cdc.gov / 770-488-3504)

[Agenda](#)

I. Welcome

II. Examples of Data linking systems

- Craig Mason – Maine
- Garland Land – Missouri
- Sherry Spence - Oregon

CENTERS FOR DISEASE CONTROL AND PREVENTION
EARLY HEARING DETECTION AND INTERVENTION
AD HOC GROUP TELECONFERENCE

NOVEMBER 5, 2002
2:00pm (eastern)

Captioning Provided By:
Margo Bachner, CSR, RMR, CRR
Caption First, Inc.

KRISTA BIERNATH: Good afternoon. I guess we'll go ahead and get started. This is Krista Biernath from CDC, and I'd like to welcome all of you to this month's Early Hearing Detection and Intervention Ad Hoc Teleconference. Today, the subjects will be on data linking systems, and an update on the cochlear implant and meningitis investigation that CDC has been involved in. I'd like to remind you to please mute your microphones when you're not speaking to help reduce the amount of background noise. Today's conference is being recorded and the transcript will be provided on our website.

Before we begin, I do have a couple of announcements. As mentioned in the notices for today's conference, our first three speakers have provided us with slides that are available on NCHAM's website. If you have not already downloaded them or are going to view them during the teleconference, you can find the link to the slides on NCHAM's website in the teleconference website. And I'd like to thank NCHAM for agreeing to put on the slides on such short notice.

The second announcement is that we will be sending a request for your input on future ad hoc teleconference subjects. We will be asking for your suggestions on topics or specific presentations that you would like to have on the teleconference. When you get this e-mail, please take a few moments to reply. Are there any other announcements or comments from the participants?

Okay. Our speakers, who will be discussing examples of data linking systems, are Craig Mason from Maine, Garland Land from Missouri and Sherry Spence from Oregon. And then Jennita Reefhuis will be giving us an update on cochlear implant studies.

Craig, if you're on, you can go ahead.

CRAIG MASON: Okay. I'll start then. The PowerPoint presentation that I'm referring to that is titled childlink.dps, you should be able to click on that and it should open up automatically for everybody.

My name again is Craig Mason. I'm an associate professor of education and applied quantitative methods at the University Of Maine. And our project that we've been working with the Bureau of Health is titled Child Link, the software system that we've developed. I'm assuming at this point that everyone has had time to load up the PowerPoint slides. So, I will move on to the second slide, which is titled Project Description, so we can all kind of stay together on it.

What our project involves is a collaboration with the Bureau of Health and the University of Maine. This really grew out of a desire between the University and the Bureau of Health of strengthening ties between the two groups. The project began specifically with the EHDI program, but the goal from the start was to expand the system more broadly into other areas of child development,

including birth defects, developmental disabilities and other areas. The project is really focusing on informatics for integrating database systems.

Our objective with trying to integrate existing systems -- had several reasons behind it. First, we felt that by integrating existing systems we would be able to get maximal information while simultaneously minimizing demands on existing systems, such as nurses or hospitals or audiologists, etc. The goal was to really provide a system that would help us to insure service and care for families and children. The purpose behind trying to link all of these systems is we feel that by putting together as comprehensive information as we can regarding a child and family into a single place we can best help to insure that children and families are able to get the services and care that can help. The Child Link involves several systems that we are linking and also systems that we've created for the state. As part of this project, we've created links for the state as well as the university program. These are linked electronically with the birth certificate and the metabolic screening as well as infant death certificates.

The next slide, which is entitled Link Data Transfer kind of summarizes the system we've put in place for sharing data and really bringing the University of Maine on a sequel server. The information is on the servers that are kept in a locked room in a building that's a secure building on campus that requires keycard access in off hours, you know, evenings and weekends. Any access to the server has to occur through a dual firewall system. What that involves is, we have two separate firewalls with what's referred to as a DMZ zone separating them so that basically if someone from the outside is trying to access the system, particularly if a hacker were trying to access the Child Link data, they would get through the first firewall and find themselves with an entirely new firewall in front of them that has a different method of accessing it than they just used to get from the first one.

So, the idea would be that any hacker that was able to successfully get into the first firewall would be trapped in this DMZ zone and would be able to be expelled from the system before they could actually get to any of the data. The entire system is actively monitored 24/7 by a company that we can contract with. So, what that involves is rather than just logging any unauthorized or inappropriate types of access to the system, the user could actually be kicked out of the system all together if it happened they were doing something they weren't supposed to be doing. Part of the benefit of again, all of the access goes through the Internet. Even at the University the Child Link faculty and staff involved with the project, if we want to access the servers, we have to go out -- even from over just down the hall, we have to go out from the university, into the internet and back through this firewall. The idea is we want to minimize the number of entry points to the server so it helps us to really beef up the security and minimize potential ways that someone could access the data inappropriately. The hospitals that are involved with doing the hearing screening are using almost all of the State of Maine hospitals are using NADUS, and the hospitals can then log onto the server and download the data book directly on to the server so that it doesn't really require any additional work on the part of the hospitals that are doing the hearing screening. If the hospital doesn't have the data book, we've actually created a stand-alone database system that hospitals can have free for gathering the same information electronically, which they can then download directly on to the server. Other providers and the Bureau of Health can similarly access the data through the Internet.

The Bureau of Health has coordinated a meeting with audiologists around the state that are working with children and outside of providing universal support, an interest in the entire project. So far audiologists have all consistently reported they would like to have Internet access. So, their access will come through the same way. So, we're looking at a scantron option for people that

don't have Internet access or are uncomfortable with Internet access. So far audiologists have indicated the preference for accessing the data, for inputting their data through the Internet.

The next slide titled Child Link Linkage Process, actually it's a very simple summary of the process we've designed for linking data. The idea is as we get different data from the state, whether it's the electronic birth certificate or information from hospitals on the EHDI screening or the metabolic records, whatever the different types of data that is put into the system is first standardized. All the various fields that we will be linking on are all standardized. For example, names, date of birth, mother's name, place of birth, etc., so that different systems are all having the same types of fields.

We then try to link any new information, any new identifying information with our existing table to determine whether a match is found, then the person is assigned a new I.D., and we store information regarding up to 14 different identifiers for that person and assign them a Child Link I.D. So, we record, the metabolic record. We assign our own unique I.D. for every individual. If there's a link found, if it appears that that person already has a record in the Child Link database system, there's actually two ways that can be done. One is if we find an exact match. So, for a cross of up to 14 potential linking fields, we find an exact match, the same person, same mother, same date of birth, same location, etc., then for that record they're automatically just assigned the existing I.D. out of the Child Link database.

Alternatively, it's possible that we could have what's called a probabilistic match. That's a case where you don't have an exact match with existing records. For example, it may be one of the classic examples we've used from previous work involves a colleague of ours with the name Jose Szapocznik. And an uncommon last name. And if you find two people born on the same date but the name may show up one time as J. Szapocznik or Joe Szapocznik, and then another database may show up as Jose, you can do statistical algorithms to determine whether or not this is the person, even though there's inconsistent data across the different database systems that you're trying to match. And as we're starting with the system, we'll actually do a manual verification of all of the probabilistic matches that we do to determine are we comfortable that this is in fact the same person. If our verification tells us that we are confident that it's the same person, we're going to keep track of the linkage parameters so that we can record what were, you know, the statistical results that we got that led us to conclude that this is the person. And we then assign the existing I.D. If we determine that it's not the same person, then we will assign a new I.D. And also, we store all the linkage information so that we can go back later on and determine why did the probabilistic techniques tell us that this was the same person, and when we've looked at it, it's not.

Storing that information, the idea is that over time we can fine tune our algorithms, fine tune the process so that we can understand when we don't have an exact match, how can we do a better job of identifying confidently that the person, based on statistical techniques that we in fact have the same person or not. Once we've assigned an I.D. to the person, either a new one or we've determined that someone is already in the system, we then update our field and check to see if there's more records.

If there's new records, we repeat that whole process with the next record in the incoming table. Once we're done with a linkage, one of the things that we found that's very useful is to actually then go back, and we have this little iterative feedback, and it says "look" on this chart, but it should be "loop." We do this little feedback loop and we check the entire system over again. What we've found is that as you add data over time into a database, as the database grows, what we'll have is there will be ambiguities where, for example, if the ambiguities are mistakes where

you're not sure is this the same person or not or there might be an error, that future information can actually help you to clarify. And so, by having this feedback loop, what we can do is we can see if the new records that we've just added can help us to clarify any previous information that was ambiguous or in fact can help us identify a possible error that might have been made earlier or that this new information, you know, can help us to figure out. So, we basically rerun a similar algorithm looking for any errors to verify that the entire Child Link I.D. tables are still internally consistent and that we can identify any cases that we previously flagged as being a potential issue, whether we can clarify that, okay?

The next slide is titled Keys to Operational Success. And here I just want to talk about kind of two things that we've been doing that I think are actually very valuable in helping to keep the process moving and avoiding issues down the road. One is that right from the start we've worked very closely with our Attorney General's office. We meet regularly with an Assistant Attorney General who has been identified as the HIPPA expert for the State and to address any issues that the Attorney General's Office might have with the project as well as to get an independent evaluation of whether we're being HIPPA compliant.

You know, once you bring in a lawyer, it naturally slows things down. But we've found that ultimately it's worth it in that inevitably there's questions, whether from hospitals, audiologists, other providers, as to our HIPPA compliance. And the fact that we're able to point to meetings with this expert in the Attorney General's Office nearly always eliminates concerns that people may have. So, that input has been very valuable. A second step that we've done is also, I think, key to the project. We've moved the Child Link project into our university UAP. Now they're called UCEDD, University Center for Excellence and Developmental Disabilities. And our UCEDD is a member of the University Centers for Disabilities and is one of the strongest advocacy programs for children and adults with developmental disabilities in the State of Maine.

This provides us two key benefits that led us to want to move the project into this program. One is that the nature of the data that we're working with, you know, establishing population registries for hearing loss or birth defects can naturally be a source of concern for some of these communities in the real world. By associating our project, by associating Child Link with what is widely seen as a key service in advocacy organization, what we've found is that people in the birth defects/disability community feel less skeptical of the project and our motivations for trying to integrate these database systems. The association I think helps people that would otherwise be concerned to be more open to learning about the potential benefits that such data integration may bring rather than focus merely primarily on the potential risks that are involved.

Our UCEDD really is an excellent partner in helping to explain and validate the need and benefits of our work to those in the community who would likely be the most uncomfortable with a project integrating data in this way. So, in the long run I think it's a huge benefit that's already proving valuable to us. Also, UCEDDs are well-connected with programs around the state as we felt this was extremely valuable for us as we worked to expand Child Link, particularly into service delivery data. For example, our next step is to directly connect the Child Link database with the state's children with special medical needs information system so that we can get additional service delivery data on all of these kids. And fortunately, the children with special medical needs program at the Bureau of Health is already collaborating with our UCEDD on a variety of projects. So, they're already comfortable with sharing data with us. So, it just streamlines and eases that whole process of trying to expand Child Link into other domains.

The next slide is titled Features of Child Link. I don't want to spend time going screen by screen of what the database system looks like. There are actually just too many screens to show all of

them. But what we've got is a summary screen of a hypothetical case to kind of highlight some of the information and kind of the way the nature of Child Link. As you can see here, we have a hypothetical child data on Cham Brady. And you can see that what Child Link does is it actually brings together these disparity systems that are previously unconnected. All in one place a Bureau of Health official is able to access information on the hearing screening and diagnostic testing on birth defects, on metabolic disorders, on the metabolic screening, as well as additional information related to the child's birth and family background and tracking information for the child and the family.

When someone accesses -- when a Bureau of Health official accesses the system and they come to the screen for an individual, an algorithm -- the program actually runs an algorithm. For example, the hearing and birth defects are highlighted in red. What that would tell them is there is something atypical for this person in those areas. So, for example, without going through all screens, Cham is identified as having spina bifida, and also as being referred for her hearing screen. So, this way someone can very quickly see if there is any need for taking a closer look at some of the other data rather than having to go through countless screens to check that everything was all right or if there is a concern.

For example, with a hearing screening you can go from this screen to get detailed information on the hearing screen, any diagnostic testing, all diagnostic testing, all hearing screens that have been performed, as well as service delivery information. The same can be done with birth defects. In fact, it leads seamlessly to the electronic birth defects registry, as well. So, any child with both birth defects or a hearing screen or one or the other, all that information is shared seamlessly.

The next screen talks about security and access. And really, in terms of talking about some of the key features, I really should highlight the security aspects of this. I need to point out the previous screen where we're actually able to see detailed information is really limited to a small number of state public health officials. Hospitals and providers, for example, cannot access data that they did not directly enter into the Child Link system. So, for example, one of the things hospitals have raised is a question that they would like to access not just hearing screening information on kids that they've screened, but also look at the child's birth certificate. The feeling is the hospitals collected birth certificate data, so, you know they're the ones that collected it and entered that into the state's vital statistics system, that it would be convenient for them to also see that information all in one place.

However, through our consultations with the Attorney General's Office, we're not able to do that. They've deemed the hospital's input, metabolic records, input birth certificate records, even though they collect the data, they put it into different systems, and being we're getting the data from a different system than the hospital, we cannot actually connect those -- we can't make those connections for them. Any one hospital or provider can only access information that they've directly entered into Child Link. I'm going to actually move on.

KRISTA BIERNATH: Craig, we're kind of running a little short on time. So, if we could maybe go to questions and answers? Is that okay?

CRAIG MASON: That would be fine.

KRISTA BIERNATH: Does anybody have any questions?

This is **Debbie Berringer** from the State of Michigan. I just have a question about the rate of duplication that you find with children in the database.

CRAIG MASON: We've only just started this. The database has been completely designed. We're only starting to get data from the state. So, that's going to take some time to determine how often that's going to be an issue. Though we're tracking -- we track all duplication, and any issue where there's inconsistencies, if there's a duplicate child, there's, for example, small spelling changes or first name -- not first name -- middle name missing, whatever, we actually keep track of all the variations that a child may appear in any system. Thank you.

CRAIG MASON: Other questions? If I could just have one second, I want to point out one of the features, and someone can go through the slides and take a look at this. Another key feature that we've designed with Child Link we're designing the system so all information can be organized on family levels. I think it's one of our key strengths of the Child Link system. It's possible to not just look at an individual child, but a Bureau of Health official, for example, would be able to access information on all of the child's siblings to see what types of needs or services anyone in the family has rather than just do child by child.

This is **Scott Grosse**, CDC. Could you give us your contact information, please, Craig?

CRAIG MASON: Sure. I should have put that on there. It's Craig.mason@umit --Is that "t" as in turtle? "T" as in turtle. -- .Maine.edu. And also, you can contact me by phone at area code 207-581-9059. Thanks.

We've put a lot of work into the methodological aspects of this, so I'd be very happy to talk to anyone that has questions.

KRISTA BIERNATH: Okay. Thank you. That was really informative. Our next presenter is Garland Land from Missouri. Are you on?

GARLAND LAND: Yes, I am. This chart has the hospital at the top. This is a simpler slide and kind of gives the overview of how we started our approach. And I want to talk about what we learned from this and the direction that we're going now. We redesigned our metabolic form with newborn hearing questions on it with the intent that the hospital could fill out the hearing questions on that form and send it into our state lab. We also provided a separate form for hearing only if the hospital did not complete the hearing questions on the metabolic form. We didn't want to hold up the metabolic form coming into the lab. This allowed the hospital to complete a hearing only form and send that into us.

We then provided a web application that we were wanting the hospitals to use that had the demographics for both hearing and metabolic along with the hearing questions. Our intent was that if they would use the web application, then they wouldn't have to complete all the items on the paper form that was to be sent into us. Obviously you still have to send in the metabolic form with the blood spots on it, but they wouldn't have to complete all the data elements that they use with the web application. The forms and the web application go into a Neometrics system. Neometrics is a company that has supported our lab in the past for metabolics. And they expanded the system to include hearing.

We also have a web-based system for audiological results. When the child goes to the audiologist, the audiologist can enter their results into the web application, which goes into the same database with the initial hearing results. From that point on, then, there's a case management system in Neometrics that allows us to send out the notifications by fax and by mail to the providers and to the parents, for both metabolic and for hearing. We also have from that

system the ability for hospitals to get access to web-based reports for their own children on the hearing results. And they can get both statistical reports and child listing types of reports.

Let me go back up to the upper right-hand column. The hospital creates the birth certificate. They use our electronic birth certificate system provided by Genesis and modem that data into our birth registry. That data file then is moved into our MOHSAIC application. MOHSAIC is our integrated information system for all children's activities. Actually, it's broader than children. It's all public health activities in the department. And so, immunizations are entered directly into MOHSAIC, lead screenings are entered directly into MOHSAIC, special health care needs, case management information is in MOHSAIC, Medicaid encounters are in MOHSAIC, WIC is linked to MOHSAIC. So, all the information on a child is in our integrated database there. These are not separate files. This is a tightly integrated system. The data then from the newborn hearing and metabolic screening then is linked into MOHSAIC. We include the medical record number of both the mother and the child in our newborn hearing and metabolic screening database from Neometrics. And then we also have those numbers on our birth system. So, we have the medical record number of the mother and the child, the hospital, the name of the child and the name of the mother and the date of birth. All these data fields are in both the birth system and the hearing system. And so, that allows us then to link both of those district files into MOHSAIC. Then out of MOHSAIC, once we have all that information from immunizations, special health care needs, hearing and metabolic, we're able to create what we call our stoplight system, which is a web-based application for providers, so they can go in and enter a child's name, find the child and on the top of the screen -- I didn't make a slide of this to show you, but it shows on the top of the first page red bars and green bars. A red bar would be if the child doesn't have immunizations or doesn't have lead screening done or whatever, hearing hasn't been completed, it would show up as a red light. And if it's a green light, it would be everything is okay. All the data is presented on one system. And they can get the more detailed information in terms of the actual result, the actual immunization or the actual lead findings or actual hearing results.

This is what our physicians asked for, particularly in emergency rooms when they have a child coming in that they haven't had in the past and trying to find out more information about the child.

Let me tell you what happened as we started implementing this. We found that the hospitals didn't use the combined metabolic hearing form the way we had expected them to. The metabolic people are separate from the hearing people. And so, the hearing people preferred to just complete the hearing only form, which meant that they had to fill out a separate form with all the demographics, which was already completed by the metabolic people. But from a communications point of view, that seemed to be easier for them. And so, the different forms are coming in, the metabolic form and the hearing form. Well, then that has created problems because -- they might come in at different times. Our lab enters the data for the metabolic. Later they get the hearing form. They try to find that child in the same system. By that time maybe the child's name has changed even though it's right after birth. But since two different people were completing the two forms, there will be differences occurring. And so, they will have problems finding the child in the database.

The other problem that we found was the information that was on the hearing, or on the metabolic form oftentimes was different than the information that was being entered into the web system. And so, our lab people were trying to compare the two data and find differences and then call the hospitals back to see which was correct. And so, it was creating lots of issues for our state laboratory with the design that we originally had developed.

So, we decided to go in little bit different direction. That's what the next flow chart shows. This is a little bit more complicated, but I don't have to go through all the boxes with you. In essence what we're doing now is we're creating a multi-copy form very similar -- at least we've patterned it to some extent after the one that the state of Washington developed that has the metabolic form and then the hearing form underneath it. But what's critical about the form is it has a bar code that goes through the packet of the forms. So, if the hearing form is completed, it has the bar code that's the same as the metabolic. That way, we can find the child in our system and don't have to rely upon the name and demographics, which may have changed.

So, going back to the flow diagram, what we're wanting the hospital to do now is just log into the web EBP system, which is the system the hospital has access to. If they're entering from the metabolic data, they'll enter the demographics for the child. And now what's different is they're going to print a label -- after they enter the demographics, insert that label on the metabolic form. That way they don't have to complete the metabolic form any longer. Whatever information they enter in the web system, they can print it on to the label, and that label then is attached to the metabolic form. So, that eliminates them having to fill out both the form and the web screen. It also stops the problem that we had before of different information coming in from the web system and from the metabolic form.

So, if you have two people in the hospital entering data, one for hearing and one for metabolic, whichever one starts the process, it doesn't make any difference, one can put the demographics in and then the other one come back and put in the hearing results, or the hearing people can start it and then the metabolic people will find that the child is already in the application, and they can just print off a label and attach it to the metabolic form.

We still have the audiological web application, as we had before. The data then all comes into the state lab as before. It goes into the Neometrics MSDS system and into the case management system called the CMS system for the short-term follow-up, which I mentioned before, for the case management letters going out to the audiologist and providers. The data then goes into MOHSAIC, links up with our birth certificate. Then we're using the case management system in MOHSAIC for the long-term follow-up, so that when a child gets a hearing aid or goes into one of our other programs, then we will follow up the child in MOHSAIC to track their results over time.

We're just in the process of implementing this label concept and developing the new bar code form. We're testing it out with some hospitals at the moment to see if it won't reduce some of the problems that we had before. We're hopeful that this will work much better than what we've been doing up until now so that we can reduce some of the duplication of effort at both the hospital and our laboratory and the problems that we were having in both cases. Let me just stop there and see if there are any questions.

Yes, Garland, this is **Scott Grosse**. How long do you follow up children using this hearing and metabolic screening database?

GARLAND LAND: I'm going to let Melinda answer that from a program perspective. We really haven't come to any decisions on that since hearing screenings just became mandatory in our state in January of this year. We are anticipating doing it at least three years, and we're trying to see how much information we're going to be able to get from our Department of Elementary and Secondary Education folks to see about being able to follow them and getting their assistance to be able to do that on a more long-term basis. But we really haven't set any specific criteria at this point. Thank you.

This is **Pat Dewey** from Virginia. You mentioned that the audiologist has access to this database? What sort of security issues did you have to deal with?

GARLAND LAND: We don't have to have security in terms of them being able to identify a specific child. They have access to all children in the database on the hearing side. They wouldn't be able to see anything in terms of metabolic or anything else. But our state law allows the sharing of data on a need to know basis. So, they can just enter the child's name, find the child, and then enter the information on that child.

Do you keep hard copies of the metabolic forms?

GARLAND LAND: Yes. The state lab keeps those for 21 years.

KRISTA BIERNATH: Any further questions? Thank you, Garland. We have one more example of a state data linking system. Sherry Spence is going to talk to us from Oregon. Sherry, are you on?

SHERRY SPENCE: SHERRY SPENCE: Yes. Thank you. If you click on the bottom file or open up your file, you'll see an introductory screen. This presentation is a little bit interactive, so sometimes you need to go through a couple of mouse clicks to complete a screen. So, I'm going to say, "Page down," because that's the way that I found simplest to move through the screens. And I'll tell you when you go from slide to slide. We're not going to be able to get through all 26 slides, but then we don't need to. You can look at these at your leisure. I'll try to hit the high points that I thought might be most interesting to you, and then leave the rest for a later time. Page down to see what our data consolidation involves. In addition to CDC and the Office of Family Health, we're working with a number of state and local partners. And that kind of changes the flavor of our approach. We're working with the Department of Education and the Oregon Division on Children and Families as well as other partners in the Department of Human Services. Page down and you'll see the FamilyNet logo and tag lines. The FamilyNet structure is a state-maintained, locally operated and locally run, interactive system for supporting service delivery at the state and local levels.

If you page down and page down again, you'll see our first module is TWIST, the WIC module, connected to the Client Master that stores client demographic and location information. Page down to see each component of the system. Our second module is the immunization module, with a link to the statewide registry. Page down again to see the Family and Child Module, which is the part that we're developing that deals with newborn screening, hearing screening, psycho-social services, and home visiting services for children. Page down again and you'll see the remaining modules of FamilyNet.

Go to the next slide. We're linking the Family and Child Module and the WIC and immunization modules to link information about both the child and the pregnant or postpartum woman. The data capture for the Family and Child Module is started prior to delivery to achieve the best possible outcomes for the child.

As you page down to look at this slide, the flow of information for various modules appears; you'll see dotted lines coming from the immunization, WIC and maternal and child health, and then you'll see the authorized access coming up through the consolidated Family Net data. And what we get out of that is child and family -- keep paging down -- specific child and family information, as authorized by the user's roles and responsibilities and by the parents. That child and family information then can be accessible to a provider who didn't put in the data if the parents have

authorized it and the programs have allowed it. This is how we're able to have provider lookup of infant health status and yet maintain security. So, a hospital can do the heel stick, and then the pediatrician can look up the results because we've got those layers of security in place.

So, if you look at the bottom bar on this page, it says, "Authorized access by health care, public health and social service provider, by program manager and by analyst." That security is backed up first by a firewall, then by four access limitations: Parental choice—parents or guardians have the right to say, and see, who has access to their data - choice about their children. WIC, immunization and other family and child health programs have the right to say who has access to data for which they are the guardians. And our vital statistic and public health lab folks also have that right [to say who has access to the data they manage]. There are certain legislative mandates about the sharing of newborn screening information and prohibiting the sharing of newborn hearing and other screening information. And the HIPAA requirements sort of overlay that. So, our approach to security in addition to the firewall is to have password protection first, of course. But then beyond that a definition of program roles and responsibilities that takes into account the program decision and the legislative mandate, and then another layer of security that is based on parental choice that takes into account what the parents agree to share. And that actually satisfies the HIPAA requirement, also, because if the guardian or parent has consented to the sharing of information, then the HIPAA rules are satisfied.

As you page down to look at this slide, the flow of information for various modules appears; you'll see dotted lines coming from the immunization, WIC and maternal and child health, and then you'll see the authorized access coming up through the consolidated Family Net data. And what we get out of that is child and family -- keep paging down -- specific child and family information, as authorized by the user's roles and responsibilities and by the parents. That child and family information then can be accessible to a provider who didn't put in the data if the parents have authorized it and the programs have allowed it. This is how we're able to have provider lookup of infant health status and yet maintain security. So, a hospital can do the heel stick, and then the pediatrician can look up the results because we've got those layers of security in place.

Also, of course, if you page down one more time [still on this screen], we have program or population reporting out of these data. Am I running out of time? Going to the next slides -- and just keep paging down because we're not going to describe the existing infrastructures. It's complicated. When you get to the slide titled "Newborn Goals," just briefly we are going to talk about we want: both population-based information and to support and assure timely follow-up and services for children with identified need. And that security structure and data consolidation structure we are putting in place are the approaches that we're using to do that [accomplish those goals].

And we also want to start [building a database accessible to research] - now, for a starting point we'll use our aggregated and identified data to assess risks for hearing loss, and [these data should also be valuable, aggregated] for genetics research. Now, the way we do that, if you page down [to the next screen, and page down to see the components of the screen], you'll see local services to children and their families and then see linked newborn data coming into the data system. Both of those [information] feeds are coming into the FamilyNet Family and Child Module. And EHDl reporting is one of those inputs into the Family and Child Module. Finally we're looking at adding two [data feeds]: hospital reporting and birth defects reporting. Page down a few more times and you'll see the two additions.

So, you should have a picture with Family Net, Family and Child Module linked to newborn data, EHDl reporting, birth defects reporting, and then the hospital reporting. Our new addition here, in

the blue-green boxes, is we want to web-enable - The front end of that hospital reporting - so that once we get the data entered into the FamilyNet Client Master, which is what maintains the demographics for all people in the FamilyNet data system, once we get that first entry into the Client Master of the pregnant woman or the newborn, we can then key on that first data entry and not repeat it. Subsequent reporting can pull up that record that's already in the system and then add to it instead of having to link multiple records.

We know that in some circumstances we're still going to have to do behind-the-scenes matching, but we're hoping that web-enabling the hospital reporting, adding the birth defects reporting, and reporting to authorized providers – the hearing and metabolic screening reports, of course - will be a way that we're going to allow people to streamline their interaction with the system and therefore make it more effective for them.

One of the ways that we're doing this, the way that we're approaching the FamilyNet identification of individuals, is that we have a primary family ID, and that primary family ID can be associated not only with all of the members in the primary family, but also with associated family risks. Also, we have an individual ID, which is separate from the primary family ID, and individual risks and individual results. But we also have [this primary family] linking ID that allows us to link risks that are tagged family risks to members of the primary family. The structure, as we're designing it, will also allow multiple family relationships and multiple family IDs; although only the primary family ID will have family risks [that can be] associated with all family members.

With multiple family IDs, for example, if you have a family with child custody contested or with joint custody, the system is able to recognize which parent interacts with the system and which parent also has custody or also has an interest. And if the custody changes, we're able to change the primary family associations so that we can stay with the family that has custody and care-giving responsibility for the child.

If you move on to the next page, Populating Family Net Databases, you'll see that the way that we're currently bringing data in for the Family Net system is to do linking of birth certificate, metabolic screening, and newborn hearing data. The way we're doing that, if you page down, is through probabilistic matching of the birth certificate, metabolic, and hearing screening data into the linked newborn database. As we move toward bringing in the service data and the matched newborn data, if you page down again, that probabilistic matching will extend to incorporate a matching of the client master data with the linked newborn data. And that slide, where the probabilistic matching dotted line blue box is expanded, shows you first and second stage matches, with the data elements that we're using to match records.

I know I'm going very quickly here, but I'll be happy to take questions or to talk to you off-line after this presentation.

QUESTION: You said you'd give us your contact information.

SHERRY SPENCE: Yes, I will. It's Sherry Spence as spelled on the first slide, Sherry.spence@stateor.us. And the phone number is 503-731-4059. I think I'm not going to go through the [whole presentation] -- you can just keep paging down till you get through the benefits of the consolidated and child health profile goals because I think you know all of these. Page down till you get to the "Not-So-Small Side Issues" slide.

Funding issues are issues that we all face. Complexity of the system is a very serious one for us because we have not only multiple kinds of data capture and data use, but a complexity of

interactions with the system. Again, I won't spend a lot of time on this, but these side issues, as you heard from Garland's description of how data entry is working or not working, can become very central to getting the system to work. So, we spent a lot of time up front talking with our partners and meeting with our partners, and we will continue to do that, trying to figure out what's going to work best for them. And then, of course, as was Garland's experience, we'll get it out and change it again if we have to, to make it really work. You have to be ready for [changing needs]. That's the main thing. I think I'll just stop there and take your questions.

This is **Pat Dewey** from Virginia. What percentage of parents do not agree to have this data in the database and shared among the programs?

SHERRY SPENCE: Well, we don't have the [Family and Child Module] rolled out yet, so I can only give you statistics on other parts of FamilyNet. With our immunization registry, we've had less than two percent of parents who don't agree [to participate]. Our metabolic screening, we haven't had any parents who opt out [actually, over time 0.1% of parents opt out; none have opted out for the newborn data linking]. The metabolic screening information sharing is not up to them. State law requires that if they agree to the metabolic screening, that the information be shared. Our hearing screening -- that is, just who opt out of the screening process -- I think that two to four percent is a good estimate. But we don't have complete information on that yet. Thanks.

Sherry, this is **Will** in Tennessee. How do you maintain permission, especially since you have several different areas that you get permissions from, and how do you keep those current?

SHERRY SPENCE: That's a really good question, Will. It's a threefold methodology. The firewall access is through an authorized user name and password, which is maintained as a part of the firewall security. The access to the system is through a system log-in user name and password that's associated with the roles and responsibilities of the user. And it's part of Sybase security because ours happens to be a Sybase database at this point. But the security -- the roles and responsibilities -- basically assigns the user to a group which limits access at the program screen or even data element level. We don't go down to the data element level because the maintenance is too difficult. [Roles and responsibilities are defined by the requirements of the program that supplies the data and the needed access of the user's role with respect to the data system.] That security is maintained -- will be maintained for internet users -- in Salem, Oregon, our state capital, where the database administrator is. It will be maintained for county local Health Department users at each local Health Department.

And then the final level of security is the parental consent security. And that will be maintained at the local Health Department. And that's based on a screen entry that's sort of a check box of what the parents signed for consent. And then that limits or opens access within the FamilyNet system based on parental consent. That will be maintained for internet users in Salem and for local Health Department users at the local Health Department. So, part of the answer is that the security maintenance is distributed among three different groups. Well, the third group is local health departments. And that's 36 [counties and 32] health departments. And that sort of spreads the load a lot.

Will Oden: This is **Will** again. So, if you have one of those users that provides that certain role, if they leave, how do you handle that?

SHERRY SPENCE: The security is supposed to be maintained on a real time level so that if somebody leaves, one of the exit responsibilities of the security maintenance--of the person's supervisor--is to remove that person from all data systems. That's sort of the exit checklist. With

security for hospitals and providers outside of the state Health Department and local Health Department system, we need to maintain parental consent periodically. So, we need to update that parental consent periodically, and that's when we'd change the security.

QUESTION: Do your permissions have a certain time frame on them, like a year or two years?

SHERRY SPENCE: It's more like six months or a year. Okay. Thank you.

KRISTA BIERNATH: Any other questions? I just want to say thank you to the three of you. This has been really an informative teleconference. We were going to have Jennita Reefhuis from here at CDC, the lead investigator of meningitis and the cochlear implant investigation, talk. However, she's been out in the field gathering data, and I've been getting word throughout the conference that she's basically in transit, shuttle bus, and airport. She's now boarding the plane. So, due to travel, this has been a hectic day for her. She will not be able to speak to us from the airplane and so I apologize that we are going to have to reschedule her update to the next conference call in January. We are making information about the investigation available on our website.

Before we close, I just want to ask if there are any other announcements that need to be made?

Okay. The next teleconference is January 7th. Remember to please reply on the e-mail that we're sending about suggested topics for the teleconference. Those will be very helpful. And I want to thank you all for participating and a special thank you to each of the speakers.