

Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference
May 4, 2004

Topic: Part C Services for Children with Hearing Loss

TO: Ad Hoc Group for EHD
FROM: Marcus Gaffney
SUBJECT: Conference call-in number and agenda.
DATE: May 4, 2004

The next EHD teleconference will be on Tuesday, **May 4, 2004** from 2:00 to 3:00 pm **Eastern** time. To join in, call toll free: **866-842-6975**. You will be greeted by an automated voice and asked to enter a CONFERENCE CODE. Dial **Code 218840**. Please call in 5 minutes before the conference starts so we can begin promptly at 2:00pm. If you have any questions, please contact Marcus Gaffney (MGaffney@cdc.gov / 404-498-3031)

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Agenda

- I. Welcome
- II. Massachusetts Part C Services
- Janet Farrell
- III. Michigan Part C Services
- Nancy Peeler

CENTERS FOR DISEASE CONTROL AND PREVENTION
EARLY HEARING DETECTION AND INTERVENTION
AD HOC GROUP TELECONFERENCE
May 4, 2004 2:00pm (eastern)

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>>Danielle Ross: Our speakers are Janet Ferro who is the program director for the Massachusetts program and Nancy Peeler who is can the Michigan part C program that's call the early on. Before we start, does anybody have any announcements or general comments? Okay. With that, I would like to welcome our first speaker which is Janet Farrell from the Massachusetts EDE program. Welcome, Janet.

>> Janet Farrell: Thank you and I would like to thank you for asking to you talk about our Massachusetts early intervention program and how it works with the universal newborn screening program. Basically, I would like to begin with a little built of history about our program. I will then talk about data collection, a little bit about funding and information on early intervention and eligibility. In Massachusetts, our early intervention program began back in the early 1970s. So we have a pretty rich history in Massachusetts with our early intervention program. Our newborn screening log loss was test in the early 1938. It was appraisal for 25 years getting ready for the very important initiative. We did have quite a bit of history working with families with children with hearing loss with a high risk program am we had the first loss -- law passed in the nation was back in 1971 that set up a system. After technology became available, we realize how important it would be to begin a universal newborn hearing screening program. So in 1998, the law really kicked off this new initiative. All births are screened prior to discharging from the hospital.

Right now, I am happy to announce that our hearing screening rate is very close to 100%. We're very proud of that. We do have a system set up for follow-up to insure that families get back for follow-up. I won't talk a lot about that toy. We're feeling very pleased with how things are going February for a follow-up system as well. State law also requires the department of public health which is where our program sits to approve the audio logical testing centers. We require centers to refer families with children diagnosed with hearing loss to early intervention. It is nice that we have that piece in place. I should acknowledge that Tracy [inaudible] from our early intervention program is on the call. She works very closely with us and would be available for questions as well as I will be available for questions. Our universal screening program has an outreach staff who contacts every family soon after diagnosis and encourages families to enroll in early intervention. We feel that is a really important connection that is made.

We are the lead agency the department of public health in Massachusetts and luckily, our newborn hearing screening program is the same division, the division for perinatal and early childhood help as the statewide early intervention program. So it allows us to work very closely together on a day-to-day basis. We have another feature, I think, that is of a program that is very important. The early intervention program has a staff person who is Tracy Osbar on the call available for early intervention staff for issues related to children with hearing loss. Trace sea wonderful resource. When parents call and have concerns about services and concerns about the services they are receiving and often works with individual early intervention centers to insure the families needs are met. She has periodic updates and she is the lead or low incidents committee and she has developed a tremendous number of resources for families with children with hearing loss and vision. She focuses on issues related to vision and autism. She helped me with the presentation and we were talking about some of our audiologist have recently

been telling us they're seeing a greater number of children going in for audiological follow-up that have either pending diagnosis of autism or have diagnosed with autism.

The universal newborn hearing screening data collection system is called the childhood hearing data system. And the early intervention program has a data system called the early interassociation information system. Both of the systems work together. The childhood hearing data system collects it from [inaudible]. We get reports back from audiological testing centers that see the children in early intervention and also parent reports. The early intervention system tracks client information, which is the children in early intervention and service delivery. The universal newborn hearing screening program staff recently received legal permission to link to early intervention to look at aggregate data and both of our programs are beginning to work with Juan Debassio and a CDC [inaudible] to begin to work with the pal data system. And it is a project that is looking at longitudinal data and it is linked to improving early intervention referrals. I will talk a little bit about funding for both early intervention and for the newborn hearing screening initiative. And Massachusetts insurance paid for services and hearing screening. The hearing screening, of course is separate from early intervention. Insurance pays a cap of 3,200 annually for services on intervention services and the department of public help pays for services after that. Division of medical assistance which is the Massachusetts they oversee the Massachusetts Medicaid program. They also reimburse for early intervention services. And reimburse for hearing and audiological follow-up. The cost to families is a small annual participation fee.

So the early intervention program and Massachusetts also has a hearing aid program for children. And that serves families in the early intervention system and that is how the Medicaid program also pays for hearing aids. I am going to talk just a little bit about information on early intervention and eligibility as well. EI serves approximately 25,500 children. We're projecting that from the year 2004. So basically in accumulative count, that is about 10% of the population. We look at 82,000 children born a year. If you look at a 3-year period, that is about 246,000. We're serving over 10%. What we -- when we look at an average it, really closer to about 6%. If you look at the national average it is about 2%. So Massachusetts serves a great number of children. It has risen incredibly over the last several years. An example of that would be back in 1989. We were serving approximately 7,000 children and 15,000 in 1996. So we've almost double that would be from 2004 to from 1996 until 2004. Some of the reasons for growth in the early intervention program that we've recognized are increased number of low birth weight babies including extremely ill infants that have surviving now that may not have survived previously due to improvements and medical care and technology. There are more multiple births. There are older moms and I know at one time I am not sure if it is still true, but Massachusetts has the distinct of having the larger number of older moms in the nation. There are many foreign adoptions that occur in Massachusetts and many of those children do utilize services through the early intervention program.

Further more, increased acceptance and recognition of the program and of the importance of the services delivered by the public by parents and provided has certainly could and we a tremendous amount of collaboration with other state agencies and the of the state agencies make level to the early intervention program. Earlier intervention serves families with children from third birthdays. They -- eligibility is for children not reaching age appropriate mile stones and children at risk for developmental delay due to biological or requiremental factors. They have been diagnosed with conditions that can result in developmental delay that would include hearing loss. The average length of time a child would be in the early intervention program in Massachusetts has been estimated to be approximately 12 months. And the average service utilization both four hours per month. It is expected that children that are identified with early hearing loss early the will enter intervention earlier and for a longer period of time much the degree of hearing loss and other factors has the types of services.

Our programs in Massachusetts are community based. We have 63 sites in Massachusetts. And geographically, we're a pretty small state. So we think that they're pretty well situated so families can receive services close to home. The intervention services occur in a most natural setting usually home based. They can occur in child care and other community sets or programs. Specialty promise for children with hearing loss including parent infant programs for the deaf are also utilized by families. There are five developmental domains identified or sometimes we make it to six developmental domains: Cognitive developmental, physical developmental which would be [inaudible] developmental, communication development, social and emotional development, and adaptive, which helps development. Our program is family centered and it focuses on strength. Thirty percent of children are referred to early intervention before six months of age. So there is a large percentage of kids that do come to early intervention soon after birth. The early intervention team is families and professionals and it includes developmental specialists, physical therapists, speech language staff, psychologists, occupational therapists and more. The individual family service plan is written with a family as a partner and includes plans to attest outcomes. Services provided are therapeutic and developmental. Sources include primary care providers, hospitals, families, families choices encourage and respected for communication options chosen.

Most communication options are available in Massachusetts. Early identification provides families with the opportunity to explore options and families they decide to try a variety of options. Our staff needs to be provisionally certified by the department of public element. There are now teachers cochlea implants and special sign language instructors who are available to work in conjunction with early intervention programs. Some are private consultants and others with staff and other agencies. Massachusetts is fortunate to have a Commission for the Deaf and Hard of Hearing that works closely with the early intervention in many programs.

The children specialists that work at the Commission for the Deaf and Hard of Hearing provide families with care coordination service that provide home visits. They may participate on individual family service plan teams. They provide technical assistance and public education for families in Massachusetts. Early intervention also has a family sign language program that is free of charge. It is taught in the home to families and includes 20 sessions. Families can take advantage of this program. It's wonderful. Families and children learn sign language with a deaf instructor and can invite other families, friends and baby-sitters and others to learn sign language.

In closing, I would like to just make a few additional remarks and then if people want to ask questions, please feel free. The universal newborn which is our Eddie program provides early intervention kids and include specialty programs and options for communication, books, websites and other helpful information. So we really see it as our job to help educate the early intervention system as a whole by providing these materials. All State should have a copy of that. It was provided at the national Eddie conference. The universal newborn hearings screening program has gone to meet with the specialty service providers that work with children with hearing loss. So they're familiar with us and people should call us if they have questions. The department of health approves the audiological diagnostic centers three times per year, where infants and children receive audiological evaluations.

We provide training and early intervention and family sign language program and other important topics. This coming week, we have a session on the [inaudible] hearing loss. We provide information at the annual early intervention conference, which is attended by hundreds of people and many professionals also working in the early intervention. We've had work shops at that conference as well as we always have a table. And both the universal hearing screening loss and intervention program has parents working in leadership roles and programs. We really hold many of the same values and having parents work in leadership roles is very important. Both have advisory committees that include consumers, professionals in the field, [inaudible] from higher Ed, people from the insurance industry and others to assist in guiding that program. Staff from both our programs work together with other state agencies and programs that serve young children and their families. One of our greatest strengths is on going collaboration with staff from both programs through daily work and staff meetings and strategic planning. And both of our programs were for colleges and university programs provide training to students that may end up working in the field of early intervention of audiology and early discipline. Thank you for your time.

>> How many audiology centers do you have?

>> Janet Farrell: We have 26 centers.

>> Did you have to go to [inaudible] to get that or were you able to advocate internally for that within your own department of Ed?

>> Tracy Osbahr: It is \$100,000 for that program. It serves somewhere between 30 and 50 families a year. Actually, it is money from the early intervention allocation.

>> Is it from part C funding?

>> Yeah.

>> Hi. This is Jan Rubenstein from Minnesota. Tracy, I have a question for you. So you are putting in as part of your part C plan, your state plan \$100,000 or are there state dollars in there?

>> Tracy: I am not positive. I can check in the e-mail. I think they are part C dollars.

>> Federal part C dollars in.

>> Yes.

>> From in your straight plan?

>> Yes. And the lead agency for part C?

>> From the public health.

>> Health, right?

>> Yes.

>> Okay. So you're essentially providing early intervention services through that. You are augmenting what is going on?

>> This is Shelly West from California. I have a question about children who are deaf, but also have other disabilities.

>> We have children with slightly different [inaudible] and have other disabilities as well. May they may not be well put into the deaf services and I wondered how that works in Massachusetts.

>> Janet Farrell: Tracy do you want to answer that?

>> TRACY: The question was about funding for children with issues and deaf. It hasn't been an issue. Janet mentioned through private insurance and of [inaudible] as well as the department of public health. I think it is always challenging for the child with multiple issues with service coordinators to insure that all of the appropriate services are provided in a timely way. Especially early on. Sometimes its is really overwhelming for families and to have a number of different providers. It is real challenging.

>> Any other questions for Janet or Tracy?

>> Did you say that there is a small fee for intervention services?

>> TRACY: There is. There is a participations fee that is based on providing income. It ranges from zero to \$250 per family.

>> MARY: This is Mary again from the commission of deaf and hard of hearing in Minnesota. I am very curious about the funding. I will probably call you back for more details, but are you able to meet -- you listed how many kids you have. How many are deaf and hard of hearing that you are working with and you said you were able to work with 30 to 40 families with the \$100,000. Are there waiting lists interpreting services or are you able to meet demand with that allocation or combination of funding you have insurance and part C dollars.

>> TRACY: Mary, that is 30 to 50 children enrolled. That is is \$100,000.

>> MARY: I know. Is there a waiting list outside of that?

>> TRACY: That seems to cover everything.

>> This is Arlene in Colorado. I am curious about the sign language program. Is that the SRP model or did you create your own program?

>> TRACY: I think we create the our own program. It has been assessed for 14 years. One of the things we feel best about it that instructors are deaf adult asked to bring perspective about deaf culture into the family.

>> Do you have the curriculum for that?

>> Yes.

>> Is it available?

>> TRACY: We would have to negotiate with the agency that provides the service, but I think they might be able willing to share it.

>>Danielle Ross: Let's move on to our next speaker. Thank you very much Janet and Tracy. I would like to welcome Nancy Peeler who is with the Michigan Part C program

>> NANCY: Hi, everybody. I am from the Michigan department of health. I am the coordinator for public health. Early on it is our program in Michigan. Our structure for part C mish mesh our lead agency is education. Our state coordinator for early on is Vanessa Winborn. We have partner agencies that work with lead agency. Those partner agency are public health, mental health in the agency that is the family's independence agency. We have an early on staff person. At each of those, we have a partner at those agency and our lead agencies soy we have a parent perspective in the administrative work. Early intervention in Michigan includes 57 service areas that have inner agency coordinate other in their local community. They coordinate a council that has representation from most of the early childhood services in that community. Mental element other publicly funded, privately funded and early head start and that sort of thing. Who actually is disabled with would vary in that community.

Our service areas for part C are determined by our special education program. Michigan is a third mandate state. When special education was create in the early '70s, Michigan decided they will create special education to cover 1st through 26 years of age. That is true. For part C which covers first to three, we overlap. That is an interesting situation because we have different eligibility criteria, but we do work closely together. The funding from the state for part C goes to an inter mediate school district. They work with local and they have somewhere between 4 or 5 local school district as part of that inter mediate school description our part C money goes to the ISDs and that is where our part D special education money goes as well. So all of it is coordinated through the [inaudible].

Eligibility criteria for part C Michigan is pretty liberal. It is our criteria is that a child has a developmental delay. We don't put about kind of percentage on that. Or they have an established health or mental or health condition that though they would delay. Our part B or special education program has the most restrict eligibility. Generally about 50% delay in those services. We also have within our part C system certain categories that you can be eligible that would be for example a visual impairment, hearing impairment or otherwise somehow some sort of impairment, that sort of thing. Our determination process in Michigan is that family would make it referred to ear or self-refer themselves to part C. Part C would be an evaluation of child development and gather the information of any kind of documentation of a diagnosed medical center. You would use that information then to work with tallies that develop the individualized family service plans. They may also be developing concurrently an individualized education plan for special education. We have made efforts to try to bring those two documents together when you have the 1st to 3-year-old enrolled in the program with any degree of success depending on the local service area.

We are serving around 14,000 children annually in part C Michigan and about 1/3rd of those children are enrolled in duly special education program. In Massachusetts, some of our eligibility criteria are more restrictive. We do not serve children as risk like they do. Michigan is very different and in how our part C system puts together. What we have is a system of services. We do not have one that is funding and that is creating quite an interesting system. When part C came into play, they took a look around and the list of services. A lot these are already available to families through other funding strengths. And the decision was to pull this all together into a system. What that may mean for families is that you may come into early on and be eligible and receive service coordination, but a lot of services would come through other funding strings that may have other rules and regulations and paperwork requirements, other the eligibility criteria and then our part C funds from our federal allocation are payer of last resort. Our services are not set up such that you have to meet a certain level of delay or the certain services are only available for certain people.

Services are available based on evaluation and based on what the parents and the team that is working with the family being that is necessary and appropriate for that child. So don't have restrictions on what a child can receive based on eligibility. Our system states we are serving just under 2.2 for and we are not getting 1% of our [inaudible]. We are not bringing in children quite as early as some of the other states are and something that we are working to rectify. We are getting close to that 2.2% that is one of the target and given our eligibility criteria for part C, we should [inaudible]. That is another area that Michigan is working to improve.

We are also working on a couple of other areas to try to improve related identification. Our initial evaluation for eligibility is one of the things we are trying to improve. It is related to the required screening or evaluation of a child's hearing and vision status. What we have been doing related to that is that this has taken funding from our parts and allocations and we have purchased screening and vision or -- I'm sorry. Hearing and vision screening equipment that has gone out to early intervention programs that they can do objective screens of children's vision and hearing and to try to do some tracking of that. If there is an issue identified, it helps to get into service. Relationship between part C and [inaudible] in Michigan is not going quite as smoothly Massachusetts described.

When EHDI started up in Michigan, it was instrumental in helping to purchase equipment that was placed in local hospitals and that was a nice connection. EHDI has made a tremendous effort to give technical assistance to hospitals about early on and about existence and how to make referrals. They have done with audiologists and provide packets of information to early on programs so they are aware of services and support that are available for families. Other states are suffering as well that we have a conflict in the Part C program with education so is guided by FERPA where our EHDI program is in public health. It is quite a lot. There are conflicts there. There are some ways to work with that. We are trying to work through, but it is going very, very slowly. We are not having a lot of success with that. And that has implications for data shaver sharing.

Even if we do not share the data, we have conflicts and the data system that is used by EHDI. In fact, for most of our public health services, they'll communicate with each issue and don't have identifiers, that sort

of thing. So even if you manage to reach the [inaudible] too long, we will have to work on data sharing. Working to try to connect the different vision and hearing initiatives is another piece that Michigan is really meaning to work on and needing improvement with. We have the EHDI program that has been a fantastic job of getting the hospitals on board on a voluntary basis because we do not have a law that requires that. We have the hearing and vision screening initiative within part C.

We do have a law that requires hearing and vision screening for school aged children beginning with entry into kindergarten and through sixth grade. To snag those pieces together so they can better communicate with each other and have places they need to go. I think one of our opportunities at this point is that we have early advocates for young children and different state agencies that are very committed to that as well. This is the best circumstances we're ever going to get and if we make service requirements and other connections and alignment.

>> This is Debbie. Since 2000 when we started collecting early intervention data, we've had about a 65% rate of return from the early intervention service coordinator providers out in the county. And we had about 560 cases of hearing loss identified. We had 363 of those children, but one thing we're seeing is that children it seems in some way the trend more recently has been that kids are getting into services sooner. We still have some ends to tie up there.

>> Are there any other questions that people have?

>> What's been your rate of growth of infants and toddlers on ISSPs for hard of hearing?

>> I can't tell you for children who are deaf or hard of hearing and the reason I want can't is that our data system cannot collect information on the reason the child is eligible.

>> What about the child counties that they – the department of Ed would report to the feds?

>> It is relatively slow. We have been bit by bit going to the 2.2%

>> This is Jan Rubenstein again from Minnesota. Yes. We need to get to that federal benchmark and the 1% under age 1. But I was just wondering we were told that we should be seeing based on our population about 600 kids on IFSPs. We're not getting there. We're creeping up year by year though. And the exciting thing is that due to the efforts of EHDI almost all of the hospitals are screening voluntarily as well. And all the babies are getting screened. Then there is getting them referred and seen.

>> I think we're starting with the same thing, Jan. to some of the other things I have heard present and I think one of the things would be a good avenue for us to work on is to make sure if they are identified during that initial screening at the hospital, how can we hook them on early to follow with that. I think that has been one of our breaks is making that referral and making that connection. What we're finding is that as our help goes on, it is due to the fact there is so much more attention to early childhood and the importance of early brain development and as there is more funding diverted. Not a huge amount but there is more being diverted and people are becoming aware of that. So our growth has been more about that than it has been, I think, to other factors.

>> You didn't see a rise in infants and toddlers identified with hearing loss or definitely over the years?

>> There is a rise in that, but that would show up in the EHDI another than in the parts C data. It is just that the qualifying condition is not recorded. I think it is, Debbie, correct me if I'm wrong, but I think some of our information birth defect shows that information.

>> DEBBIE: Right. There is another database so the birth defect registry, we find infants in there that have been reported with hearing loss and we don't have the information on them and vice versa. Our birth rates probably right around 130,000 a year. And we're screening somewhere between 93 and 95% of those babies. And then the ones that don't pass, then, of course, we want to assure that they're back with the audiologist back for rescreen, that kind of thing and then we're still trying to tighten up the

process that follow a piece from the physician helping to coordinate that and the audiologist helping to coordinate it. If they do identify a child with the piece that child is getting into early intervention services. So we're still doing a lot of work particularly with physicians and audiologists just to educate them about the services that are available in Michigan.

>> This is [inaudible] from Minnesota. How many audiologist centers do you have?

>> I think we have over 600 audiologists in the state but we only have probably about I don't know 14, 16 there's. There might be more than that. I'm just -- Ann not here today. So I am just trying to guess. They're tied in with there level 3 nursery follow-up centers and that kind of thing around the state. So I would say less than 20.

>> Okay.

>> Centers not audiologists but centers.

>> And you have identified more than 500 babies with hearing loss since 2000?

>> Since 2000 through the end of 2003, we had 562 cases of identified hearing loss. It averages out probably somewhere between 180 and 200 babies per year.

>> And then do you know -- excuse me. This is Jan Rubenstein again from Minnesota. How many kids from a December 1st trial count end up on IFSP birth through 2 in.

>> We are serving around 14,000 a year.

>> But that's all? I am just wondering we only serve like 3500, but of those, how many of those kids infants and toddlers are deaf and hard of hearing?

>> That I don't know.

>> Okay.

>> I don't know. Part of it is that we do not -- there is not a requirement at this appointment that we track that.

>> Having a lot of trouble hearing. I am sorry.

>> The other complicated factors is that a lot of those children identified with hearing loss are going directly to special education services. There is a totally different data system that tracks special education services. They may be going into early intervention, but the data system that track how many of those children fall into that can is a different data system.

>> Thank you.

>> Are there any more questions for any of our speakers?

>> MARY: This is Mary. I probably have more about funding streams, but I don't know if anybody else is interested. Maybe I can contact them individually later.

>> TRACY: This is Tracy. I was able to get to some budget pages and we validate that \$ 100,000 for the sign language [inaudible] is part of our part C budget.

>> MARY: This is Mary from Minnesota from the commission in Minnesota. I'm just wondering to follow-up on Jan Rubenstein's question to how many of your part C kids are deaf or hard of hearing?

>> We haven't count either in that way.

>> MARY: Okay. I am just curious.

>> TRACY: We are working and have some of the challenges.

>> MARY: This is mare from Minnesota. Thank you so much for doing. This is helpful. I learned a lot. I really appreciate it.

>> You're welcome.

>> Thank you.

>> Yes, thank you very much to our speakers and also to everyone who called in. It was a really informative call. And our next Ad-Hoc teleconference is on July 6th at 2:00pm eastern. Once again, I would like to thank everybody, our speakers and also everyone for calling in. And thank you very much.

>> Thank you.