



Centers for Disease Control and Prevention
EARLY HEARING DETECTION AND INTERVENTION
Ad Hoc Group - Teleconference Agenda
Topic: Parental Empowerment and Advocacy

Agenda for March 5, 2002

1. Dr. Joni Alberg, Director of Beginnings

- will discuss some of the things that Beginnings has available to parents and families with deaf or hard of hearing children

2. Pat Mejia, Executive Board Member, Family Voices - CA

- parent of child who is deaf
- will discuss some of the things that Family Voices has available to parents and families with deaf or hard of hearing children

3. Barbara Raimondo, Director of Public Affairs, American Society for Deaf Children

- will discuss some of the things that ASDC has available to parents and families with deaf or hard of hearing children
- mother of two children who are deaf

4. Melisa Engle

- mother of two 5 year old girls who are deaf
- active role in UNHS legislation in Pennsylvania

5. MaryAnn Kowalczyk

- retired mother of 38 year old daughter who is deaf
- founder of Communication Connection

CDC AD HOC COMMITTEE MEETING
EARLY HEARING DETECTION AND INTERVENTION
MARCH 5, 2002
2:00-3:00PM

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MELANIE GAMBLE: I want to welcome you to our March teleconference on parental advocacy and empowerment. I want to remind you that it's helpful if you mute your microphone when you are not speaking. Today's conference is recorded and the transcripts will be available on the Internet in approximately two weeks.

Before we begin, are there any announcements or comments from any of the participants?
Great. We will begin with Joni Alberg, she is the director of beginnings. And she will discuss some of the things that Beginnings has available for parents. If you are ready to begin, you can go ahead.

DR. JONI ALBERG: Thanks. I don't know how many of you know about Beginnings? Are there people on the line that don't know anything about us?

UNIDENTIFIED SPEAKER: Yes, there are.

DR. JONI ALBERG: I thought there would be. I'll give a brief overview because some of you do know about us. And then I'll give you our website so you can get more information after the call.

Beginnings is a nonprofit organization based in North Carolina. And we served the entire State of North Carolina, with direct services, but we also provide services outside of North Carolina, more on an indirect basis, telephone consultation and mailings and that kind of thing.

We have been in existence since the mid '80s, when a group of parents here in North Carolina were frustrated that the only options they were given when their children were diagnosed with hearing loss was schools for the deaf and a sign-based program. So Beginnings was established, and we still have the same goal and philosophy and mission today, which was to provide impartial information to parents whose children were diagnosed with a hearing loss, about alternate communication options and about all educational options out there.

And that's sort of evolved. Our organization has evolved over the years, but we still have that as our basic mission. And it's based on the belief that parents should be the ones that make the decision for their children and for their family, and not the professionals telling them what to do. And if we give the parents all the information that they need, then they can make a decision.

We have we are the first line every contact for families who have newly diagnosed children. So we are involved with the newborn hearing screening process. If you want to learn more about our set, I'll give you this now and I'll tell you more. The website is www.ncbegin.org. And there is a lot of good information there. And we link to as many other sites as we can.

The way we provide the support to parents, it's sort of a variety of way. But the primary way is with parent educators. We have 100 counties in North Carolina. So we divided the state into two equal parts, 50 counties in the east and west. And our main office is in Raleigh, but we have an offers in Charlotte, Charlotte serves the western part and rally serves the eastern. Parent educators, they are assigned

families when they are first referred to us.

We talk with notification source, particularly an audiologist. And then we contact parents and say here who is who we are, would you like us to come to your home, sit down with you, help you understand more about the hearing loss and your options? 99 times out of 100 they say yes. So we do a lot of traveling.

We will go to the home. We take all of our parents, we have a parent manual. It's free to parents in North Carolina and we provide it at cost to parents and professionals outside of North Carolina. And that information is all on our website.

Every parent gets that and it has information from, you know, the grieving process that they may be experiencing, some of -- you know, whether it's guilt or fear or denial, any of those things. Kind of go through that with them. And then we try to find out where the parents are and build from there. With newborns, we spend a lot of time talking about bonding, which is probably something you're very familiar with. They're not ready to talk about communication options yet. They just want to know if they can read to their baby or sing.

As parents of older children, though, they have a lot of questions. Everything from financial aid to reading, language development, and on and on. Our manual kind of covers all of that. And along with the manual, we'll develop for their -- depending on where they live, for that county, we provide a resource list of all of the professionals and resources that are there that can help them, whether it's early intervention, the public schools, health department, whatever.

We will provide that with names and phone numbers and e-mails, if we have it. And then we also along with all professional organizations. We also provide the parents with specific information packs, when we talk to them if they ask a specific question, financial assistance is usually a big one, we will prepare a packet of information for them on where to go to get financial assistance. Cochlear implants, we are having a lot of people that have been hearing about it, so they want to know more and we have packets on that. Pretty much everything, you name it, we have a packet on it probably.

Then we also have some video, and these also are available for inside the state free to parents and outside for a small charge. And one of them is on communication options, which covers auditory oral, auditory verbal, cued speech, total communication, American Sign Language, and we watch that with the parents. We never just leave that with them. The parent educator, sit down, explain it, they will watch a segment, talk about it, answer questions that the parents might have. And typically parents who have a child with a moderate, severe, profound, that's who is going to usually view the tape. We always tell parents with mild or unilateral or maybe moderate losses about the options, because they may hear about it and someone may say well, why aren't you signing with your child? And we want to make sure they have that information.

We also have a parent tape that has parents that are talking to each other about what it's like to be the child of a hearing loss and some people want to hear that. And then one that we call our hope tape. It's a real short, about ten minutes, called (inaudible) hear, and it's children of all ages talking who use different communication methods, talking about all of the things they have been able to achieve, even though they have a hearing loss. So it's like so what, I have a hearing loss, I still dance or I still play music or I -- I'm on the football team, so that parents really like to see that one a lot.

That's kind of an overview. In addition to the parents' initial meetings, the initial meet, helping them link with the resources, we will stay with them to make sure services are in place. Sometimes they will want to talk to another parent. We have started a bank of parents who are willing to talk with others and we try to pair them with a parent who is in the same county, but if it's a child with a unique condition, we try to find the parent of a child who has a similar condition or just like it or similar to talk with. And that is becoming more successful, and also more requested.

We have in both offices, bilingual Hispanic parent educator, they both have Spanish as their first

language and that has been a real plus for us, as our Hispanic population, as many of yours, is growing rapidly. And they have been translating our materials. Our parent manual has been translated into Spanish and we are waiting for it to be printed. We are hoping it's any time now. But we have been hoping that for probably six weeks. It's -- the state government is involved with the printing, so sometimes it takes a little longer.

We will work with the family from the time their child is born until the child turns 22. Usually it's not continuous, but we will come back at different times upon parent request, at transition times from early intervention to preschool or elementary to middle school, those are real popular times when we get calls. We help parents with advocacy, with the school, if they need it or request it. IEP representation. Our goal is to help them get the confidence and expertise to do it on their own, to be their own advocates, but we will support them or sometimes do it, if they are just real afraid. They try to come to a happy medium ground with everyone, so everyone feels like there is a win/win, and that's a great feeling when we are able to accomplish that.

In addition to all of those things, I think I covered it, we host a chat room for parents on Tuesday nights from 8 to 9. Parents call in from all over the world to participate in that or chat with the other parents. And it's parents asking parents, you know, a lot of questions about anything from deafness and puberty to lately there was someone was getting ready to have -- their child was getting ready to have a cochlear implant, they were asking a lot of questions about that. Pretty much the whole gamut. Anything a parent wants to talk about, they can. And our website talks about how parents or professionals can hook into that.

We also work with the professionals in our state who have children with hearing loss, we will do presentations, workshop, consultations. We try to get out and promote that we are here as a resource. Our health departments seem to have a lot of turn over and we want to make sure that they know that we are here and available.

Exhibits at conferences. Those are kind of the professional things, just on the side. Most of what we do, though, is with parents and families. And if I can say, we have a great staff who really are dedicated. They have a variety of backgrounds from early intervention to teachers of Deaf and hard-of-hearing, and a range in between. So we are kind of a diverse group, which is good, because our families are very, very diverse. And that's pretty much an overview of what Beginnings is and what we do. I'll stop now, because I feel like I've just been talking really fast. And see if there are questions or comments that anybody has?

MELANIE GAMBLE: I think we will hold questions to the end to allow all the speakers today. So thank you very much.

DR. JONI ALBERG: That sounds great.

MELANIE GAMBLE: Thank you for that description. Pat Mejia is an executive board member of Family Voices in California. So you can go ahead and start your presentation.

PAT MEJIA: Okay. And I'm going to apologize because I'm probably going to have to get off the call early. We are in the midst of a staff meeting as I'm speaking.

Family Voices basically is a national grass-roots effort, speaking on behalf of children with special healthcare needs. So it's kind of more global in what its focus is. And it's basically looking at the healthcare systems, and trying to make them work for families with special needs.

And there's six basic principles that Family Voices functions on. One is that every child deserves quality healthcare that is affordable and within their geographic reach. Two is that the families really are the core of the nation's healthcare system. Three is that quality healthcare should be family-centered

community-based coordinated and culturally competent. Four, health benefits and services must be flexible and guided by what children need. Five is that family professional partnerships need to be strong and work together to improve decision-making.

And the last one is that families practice cost effectiveness and expect the same from healthcare systems. So, basically, Family Voices doesn't support any specific healthcare reform plan. Instead, we kind of advise and make sure that children with special needs are kept on the agenda when plans are being created.

The primary work that Family Voices does is that it's a clearinghouse for information and education around special healthcare needs and the healthcare systems. We work a lot with the public and private sector, the media, policy makers, and other family, and it's done through a network of volunteer and actually now we have some chapters of paid coordinators throughout the country. So there's one volunteer in every state.

And then to kind of pull that altogether, there are also what are called regional coordinators. The organization that I work for out in San Francisco, Support for Families, actually coordinates the California network. In California Family Voices is run a little different than the rest of the country, just because geographically it's so large and diverse. So there are what are called family resource centers throughout California. There is one in every single county and there are 14 that sit on the Family Voices of California committee, and we work together to do California, to focus on California's needs around healthcare. There is about 40,000 members, both parents and professionals that are part of the bigger Family Voices family. And I think that's probably the main focus.

As far as Family Voices of California and more specifically San Francisco, what we do is family resource centers is we basically provide information, education and parent to parent support to families and also the information and education piece to the professionals who work with our children. We do trainings on healthcare system, getting your insurance to say yes, how to write letters, that sort of thing. We do self advocacy training for families and also in the hopes that eventually, you know, we teach our kids.

I have a 15-year-old daughter who has multiple disabilities, and I'm watching her evolve as a self advocate, and that's our ultimate goal. We also do trainings on the IEP process, the ISF process. We have a phone line. We have different support groups. We have a parent mentor program, which sounds similar to what Beginnings does, again just matching families around either the diagnosis of their child or issues that they are facing as the child grows.

We have an in-house library that has audio, video, books, and toys to be lent out to the community. We also have a new (inaudible) that goes out four times a year. And everything is done free of charge, as far as support for families is done in California, everything is put out in English, Spanish and Chinese, because those are the populations that we serve. And that's basically it.

The website for Family Voices is: www.familyvoices.org. Again, there's tons of links. It's a great site to visit. It will also connect you to the other groups. Your local groups, your Family Voices contact if you want more local information for a family, of where to call, that's where you would find that information. And that's about it.

MELANIE GAMBLE: Well, great. Since Pat has to leave early, we will take questions for her now. Any questions?

UNIDENTIFIED SPEAKER: I'd like to ask, for this training on the IEP and ISFP, how many people are doing this and where did that kind of -- who was the first person who started it, who had all the information so that they could go out and start training throughout -- wherever it was needed?

PAT MEJIA: I don't know that I know who first started it. I'm sure it's been going on since the inception

of IDEA. I know that our focus is looking at the law and also looking at it from a parent perspective. So that we don't just -- what we find happens often is we work with a lot of advocacy groups. And they're wonderful and they're necessary, but oftentimes they get locked in the legal box. And what we find with families is families come to the table with a little more creativity. So we're still keeping within the law, but we might look at things a little differently and actually be able to change the way services are provided, so that it still falls under the law, but it's just a better way of doing things or an easier or cheaper way of doing things oftentimes. So that's kind of the way we present it.

Our funding, as support for families in San Francisco, as far as the IEP trainings go, we get funding through the parent training and information center grants from OSEP, the feds. So that's where that comes from, primarily, but we do also get local funds to do it as well.

MELANIE GAMBLE: Are there anymore questions for Pat? Okay. Well, then we will move on to our next speaker. Thank you very much,

PAT MEJIA: Sure, thank you.

MELANIE GAMBLE: Thank you for that overview. Our next speaker is Barbara Raimondo from the American Society for Deaf Children. So, Barbara, if you're ready, you can begin.

BARBARA RAIMONDO: Thank you for the opportunity to talk about the American Society for Deaf Children on this conference call. ASDC is a national organization providing information and support to families to help their deaf and hard of hearing children gain meaningful and full communication access, particularly through the competent use of Sign Language, in their home, school, and community. Children of our members use a wide range of communication modes and technology including signed English, spoken language, hearing aids, assistive listening systems such as FM systems, American Sign Language, cochlear implants, and cued language.

Founded in 1967, the American Society for Deaf Children provides a number of programs and services, including a quarterly newsmagazine, bi-ennial conventions (the next to be held in Austin in July 2003), a toll free information and referral line for parents, an e-mail service for legislative information, a lending library, and a First Year Free membership program for parents of newly identified children. We are involved in a wide range of advocacy activities, including those related to newborn hearing screening, the Individuals with Disabilities Education Act, and communication accessibility. Our advocacy activities have included filing comments to the U.S. Department of Education on the Individuals with Disabilities Education Act, including Part C, filing comments to the Federal Communications Commission on access to assistive listening systems and captioning, and meeting with Congressional and Administration officials to educate them about the language and communication needs of deaf and hard of hearing children and their families.

We work closely with other advocacy groups. We are a member of Consumer Action Network, a coalition of, by, and for deaf and hard of hearing Americans, and we are a member of the Council on Education of the Deaf, which certifies teachers and programs in deaf education. In conjunction with the National Association of the Deaf and Communication Services for the Deaf, this past fall we sponsored the Deaf Children's Symposium which brought together over 400 parents, deaf and hard of hearing consumers, and professionals to learn from each other. We are a member of the Families and Advocates Partnership for Education, through which we receive and disseminate information on the Individuals with Disabilities Education Act to parents and work with administrators and policy makers to promote better understanding of IDEA. Through our membership in the Council on Education of the Deaf, ASDC is involved in the Joint Committee on Infant Hearing. We are also part of the National Deaf Education Project (NDEP). NDEP was established in 1998 to advocate for reforming the current educational delivery system for deaf and hard of hearing children. The purpose of the project is to work for a communication-based, quality educational system that recognizes and

provides for language and communication access, language and communication assessment, and language and communication development for deaf and hard of hearing children.

As you see, many of our activities revolve around what happens after the child is identified with a hearing loss. Hearing loss doesn't go away, and it is important to address the language and communication needs of deaf and hard of hearing individuals throughout their lives.

The American Society for Deaf Children is governed by a board of directors, the president of which is a parent of a deaf or hard of hearing child. The board meets twice a year and is not only involved in policy making for the organization, but is also involved in many of the daily activities. Board members pay their own expenses associated with board membership, including travel to meetings, conventions, and other events.

The American Society for Deaf Children is an independent organization that supports itself financially through memberships and our own fundraising efforts. We are not part of a larger organization, and we do not receive funding through a government entity.

One of the things we do on a daily basis is talk to parents on our 800 line, so I wanted to talk a little bit about what parents call about. The phone calls on our 800 line cover a variety of questions and concerns, from trying to obtain flashing lights so that the child knows when the phone is ringing to people trying to find deaf or hard of hearing children to adopt. However the most common calls are:

Newly identified children. Parents are seeking all the information they can find. ASDC has a packet of information we send out to parents of newly identified children that includes fact sheets on a number of topics they are asking about, such as decision making and early intervention systems. As I mentioned, we have a lending library and First Year Free program. They also want very much to talk with parents of children with hearing loss. When possible, we make a link with other parents in their area. Since I am a parent they often ask me about my experience. I also talk to them about the research showing positive outcomes for early identified children who receive appropriate early intervention and who have involved parents. During the call I am always sure to check with them about whether their child is enrolled in early intervention and whether the child has been evaluated for hearing aids. I try to answer their questions, and if they ask something I cannot answer, I refer them to another organization. I encourage them to call back if other questions arise. My goal during these conversations is to try to have their immediate questions answered, provide encouragement and affirmation that they are "on the right track," and let them know about other sources of information.

Lack of appropriate services. Most of these calls are about children over the age of three. Parents are concerned that their child's assistive listening system may not be working in school, that the captioner that the child is using is not captioning all that is being said in the classroom, they may be concerned that services called for on the child's individualized education plan are not being provided. I refer them to provisions in the Individuals with Disabilities Education Act that apply to their situation and give them some ideas about how they might go about resolving these issues. Also, we do a lot of advocacy, so these are stories that we take to policy makers.

A significant number concern the lack of services for newly identified children. While many parents, being so new to the system, do not even know what components make for a good early intervention system, other parents report concern about their interventionist. They report that they are working with early interventionists who have never worked with a child with hearing loss before. The professionals are learning what to do along with the parents. In parents' minds this is inadequate. Parents want to be able to trust that the early interventionist who is advising them and teaching their child and family has specialized training, background, and skills with children with hearing loss.

Funds for hearing aids. A significant number of calls are from parents and others seeking financial assistance for hearing aids. Although most children identified with hearing loss are candidates for

hearing aids, there are very few sources of payment for them. I hope we can keep this in mind as we are developing and refining systems, because this is a very important gap.

In closing, I invite all of you to become members of ASDC and to provide information about ASDC to the parents you see. As we say, join today so that we can continue advocating on behalf of deaf and hard of hearing children and their families. More information can be obtained from our web site <www.deafchildren.org> or from <ASDC1@aol.com>. I'll be happy to answer any questions.

MELANIE GAMBLE: Thank you. Our next speaker is Melisa Engle.

MELISA ENGEL: I have twin girls who are five years old. They weren't identified until they were 18 months old. I noticed at 10 months the one wasn't hearing as I thought she could. And the doctor put me off as a crazy mom, first time mom. I'm sure you know that out there. They were finally identified at 18 months old.

At that time, I wasn't given anything about early intervention, medical assistance to help pay for the assistive technology, anything like that. So I then started a support group for parents of children who are Deaf and hard-of-hearing in north central Pennsylvania, and then found out about universal hearing screening through our teacher of the deaf.

I started to pursue the universal hearing screening side. You know, why weren't my children screened at birth? And I went to the local hospital where my children were born, and advocated for universal hearing screening to find out that they had sort of tested like ten years ago and had stopped. At first it was not well received at the hospital. Finally, we worked together and wrote grants to raise the money to purchase the equipment. In which was used to screen babies at birth at our local hospital.

I then received a grant through the Pennsylvania disability council, to work with the 12 counties in north central Pennsylvania to advocate to the hospitals and work with the audiologists on starting universal hearing screening.

The grant helped pay for the phone bill, travel expense, supplies, postage. We did a parent pack for the audiologists to give out when the child was identified. It didn't help pay for costs of equipment. It was to help with the advocacy side of it for a year, which after a year, in the 12 counties, we had 9 hospitals up and running. And two of them were looking at equipment options, and one was just refusing until it was passed as a law.

I also worked with legislation, of course calling and e-mail and then meeting them, I went to Harrisburg several times to testify on bills, which it now is just endorsed at the end of November, Senate Bill was for the State of Pennsylvania. At the end of February, all hospitals in the State of Pennsylvania have implement universal hearing screening, so that was a big accomplishment for me that I started over two years ago.

I'm on the conference call just to talk to anybody that, you know, if they are in a state that doesn't have universal hearing screening mandated how they could promote it in their state or in their community.

I believe the law being passed is a great accomplishment. Being tested is of course the first step but I see, as the other speakers said, there is a big gap that once they are identified what happens. And we are in a very, very rural community, so there is nothing here.

It is easy to get lost in the gap. There is no good connection between the hospital screening the infants the referral to the audiologist and then into early intervention system, so parents get lost.

I also work for Parents of Pennsylvania and talking to parents and giving them their options. It's just amazing to find out parents of kids that are 15 years old or 17 years old that never knew of options and

the things with education, medical assistance, technology, so they could have their own FM trainer, etc. Thanks you for giving me this opportunity to speak.

MELANIE GAMBLE: Okay. Thank you very much, Melissa. We are going to move on now to MaryAnn Kowalczyk, who is from New Jersey.

MARYANN KOWALCZYK: Good afternoon, everybody. And I want to thank the CDC, EHDI, for this opportunity. I have a daughter who is now 38 years old and was born deaf. My experiences are quite different from many young parents now. In 1963, I gave birth to my daughter. And because I had had German measles while pregnant, exactly at 6 weeks, I suspected a hearing loss at the age of 3 weeks. And the doctors then, as some doctors do now, I was just a new mother and it was just something that everybody is looking for.

Well, finally, at 18 months old, we had our daughter evaluated, and she was severe to profoundly deaf. The audiologist here in New Jersey at that time told us that we should go to two other places and if two out of the three audiograms came back with the same message, that we should then focus on speech therapy.

Now, that's 38 years ago. Speech therapy we did. We moved to Massachusetts almost immediately and that's where she began her oral education.

Kathleen tells us now that, when she was 25 years old, she said to us, I remember communicating with you and daddy when I was six years old. My husband and I were stunned, because we didn't quite grasp communication, the word itself at that time.

Then about two years later, I went into interpreter training program at Union County College here in New Jersey. And I was absolutely stunned at the fact that there was something known as a deaf culture or a deaf life. I had instructors who were proficient, who were marvelous. The only thing that they had different from me was the fact that they used a different language than I did.

And that was a very, very sobering experience. I then joined the Parents for Deaf Awareness here in New Jersey, which is an affiliate of the American Society for Deaf Children, and I joined as a program chairman because I wanted to start to focus on deafness as culture and difference, rather than deafness as disability, because I now saw what deaf people are able to actually do.

So I have worked with this group since approximately 1991. And in that capacity I have moved their quarterly newsletter to a magazine status, and we do now include information about American Sign Language and the need for language development for children with a hearing loss prelingual.

Then, from there, several years ago, my husband and I founded a company. And it was called -- it is called the Communication Connection. And our basic goal is to go out and talk to hearing populations about deafness and what it means, about what hard-of-hearing means. Because one of the biggest things that now has begun to influence me is my association with hard-of-hearing people. Late-deafened people who seem to be shunned just as the deaf are shunned. These hard-of-hearing people are still able to talk.

But they are not able to hear 100 percent. This sets them apart. And the hearing world doesn't know much, because we don't have that large of a population of deaf people.

I had the experience of being a speaker once every year for about 8 years at Cane University here in New Jersey, where teachers of the deaf are trained. And the first year I went in, my first questions to them were: Who had any kind of reading done by a deaf author? Did they have any kind of association with the deaf people? Did they read any deaf newspapers? Did they know any deaf people themselves? And the first year not one of these students knew any of this or belonged to any of this or had read any of

this.

By the time the ninth year came, the information is becoming more and more available, so that these students who are becoming teachers of the deaf have a little more information at this particular time. However, it is still information that tends to focus generally on the technological aspects and the disability aspects of deafness, rather than on the normalness of deafness, which is then translated into the need for a separate language.

Now, in addition to that, in the -- there was an infant brain symposium in New York in 1998. And since then there has been voluminous information published about how the infant child's brain develops and why it's critical to put language into place. And that's one of the words I focus on is language, I not focus on speech. Language has a critical period in which it must be addressed. Speech will come. And it's been, I guess, helped out now by the fact that there are two psychologists from California who have written a book on baby sign, and Joseph Garcia has done his book videotape on sign with your baby. And now hearing children and hearing mothers are active in this endeavor and taught classes on this. And now my daughter is married now. She has a daughter who is 4, who happens to hear, but also using sign language and uses it. I found out that babies can talk in sign language and my granddaughter started at 5 and a half months. So it's possible and children are just phenomenal human beings.

With PDA, we focus on referral information. It's a struggling organization right now. It was much larger in the past, but since there has been so much mainstreaming done at this particular time, we are facing the experience of having to find parents who will listen as far as my child has been identified with a hearing loss. What do I do now? And they don't want to talk about deafness, culture, and difference. It's a struggle. But we are getting someplace.

Now, as of January 1, 2002, New Jersey has mandatory universal newborn hearing screening and I have begun to work with the Department of Health here to actually formulate new types of materials and brochures to be put out for parents to be given out through hospitals. Unfortunately, at the time most of the information that parents receive is still focused on the technology and the disability, rather than the rich experiences that come from being our children as normal.

And we are facing a problem, because in New Jersey we have a 2.9 billion dollar deficit and money, very very tight in coming. My experience has grown now in the last several years, because I'm a member of all national organizations that have anything to do with deafness or hard of hearing. And I am also a member of the local chapters in New Jersey, so that I receive materials from A.G. Bell Association, from Self-Help for the Hard-of-Hearing, from American Society for Deaf Children, from the New Jersey Association of the Deaf, the National Association of the Deaf. And that's about it. I'm coming from 38 years of experience, from the time when you couldn't use sign

MELANIE GAMBLE: Thank you very much, Mary Ann. I'd like to open it up now for questions. But if you do have a question, I would like for you to state your name and your affiliation before you start your question.

LAURA IVERSON: This is Laura Iverson, the Family Support Connection in Minnesota. And we support parents, parents of children who are Deaf and hard-of-hearing. And I have just two brief questions. One for Joni Alberg at Beginnings. How many newly diagnosed -- how many families with newly diagnosed children do you see a year? And for both Joni Alberg and Barbara Raimondo, do you have special resources that focus on hard of hearing children? We seem to have a lot of resources for parents of deaf children but not as many to draw on for parents of children who are hard of hearing. I wonder what you were doing on that.

DR. JONI ALBERG: This is Joni. So far this year, from July through January, we have seen 147 families that have a total of 147 newly identified children. They may not all be babies. Babies, if you look, the majority of our new children are -- or families with new babies are a year or younger. I'm looking at a

chart. We break it down in 3 month increments. 58 of those were 3 months old or less. So that is a big chunk of where our families are.

The second biggest chunk of the age group is the 3 to 5-year-olds, which is when they are transitioning from early intervention to school, to elementary school, kindergarten or the public school system.

That was the question on that. And as far as hard-of-hearing, we do have resources on that. Because we are working, as long as there is any kind of a diagnosed hearing loss, we work with families with certain unilateral losses. Because they need classroom modifications and have some special needs, too.

I'd be happy to give you my e-mail address and then -- would that work, maybe e-mail me a bit more about your question and we can talk about it further. My e-mail is jalberg@ncbegin.org.

BARBARA RAIMONDO: This is Barbara responding to your question. A lot of what we send out is not specific to one or the other. For example we have a fact sheet on decision-making and that doesn't really isn't geared towards one or the other. It's more along the lines of a process that parents can follow.

So, to some extent we don't distinguish, because we find that even children who are audiolgically hard-of-hearing can benefit from sign language or want to be part of the deaf community. So sometimes we don't make the distinction. One of the examples I mentioned was assistive technology. We do get a lot of questions about that and I do try to let -- give the parents the information they need, particularly in terms of IDEA and what kinds of things that they might want to be talking about with their school district. If they have something that I can't answer, then I refer them to another organization if I feel that that might be helpful.

I also have a whole file of brochures and information, too that I can go through. So it is a more case-by-case basis if there is something that I can't answer with what we have, I refer them to another organization or agency.

DEB LOCHNER DOYLE: This is Deb Lochner Doyle, Washington Department of Health. I have a question for Joni. How many parent educators do you have and how do you receive your funding to pay for them?

DR. JONI ALBERG: Very good question. The first one is easy. In our Raleigh office, we have four full time parent educators. And in Charlotte, we have three full time and two half time equivalents. So it's a total of four altogether. The offices have a manager. So we have eight total full-time positions as parent educators.

Now, the funding part, actually, one of our parent educators is getting married at the end of this month and she will be leaving us and I'm not replacing her until July, which is our next fiscal year, because money is an issue.

In the past, until last year, all the funding came from the Department of Health and Human Services through a contract, and it was related to legislation that was passed about the support for families. That changed last year. We now get some money from our department -- it's through still health and human services, but through the public health, through the EHDI grant. And that is -- that money supports the bilingual Hispanic parent educator in our Raleigh office and then the translation of materials and a few other things, and she also works with that program and the consultants that we have here that are working with newborn hearing screenings.

We also got a contract this year, I've been going for diversified funding, our budget was cut, the main contract that we fought last year to get an increase, 222,000, was cut by 200,000. So we are back to where we started. But I got a contract this year from our Department of Public instruction, through the division for exceptional children. Actually, the money is preschool services money. So actually, it's

federal dollars that come to the state. But then through that, they come into us.

And that is -- my justification there was that the second largest group of children whose families we serve is that 3, 4, and 5 years old. We have a small grant from the Cannon Foundation. We just started in the past year putting together a development program for raising money. We take money from anybody who will give it to us. And we're getting ready to put a -- something on our website that will allow people to contribute on line. And we're writing grants. So we don't have the most stable funding source, but we have been in existence continuously since '87 -- well, since '85. So that's a good precedent. And we have got a real supportive board right now. But it's diverse funding. That's my biggest job, challenge right now, is getting money.

MELANIE GAMBLE: Are there anymore questions?

MELISA ENGLE: Yes, this is Melissa Engle, a parent. I had a question to Joni. How are you connected with the hospitals and universal hearing screening? How do you get the referral from the hospital? Do they give you a direct referral?

DR. JONI ALBERG: No. We don't start working with the family until there is a confirmed hearing loss. So, we don't come in until after the two screenings.

MELISA ENGLE: Right. But is it through the audiologist?

DR. JONI ALBERG: I'd say over half of our referrals come from audiologists. So we have a very good working relationship. We really tried hard to maintain and develop it through, with all the birthing hospitals, the primary ones in each area and the main parts of the state.

We also, you know, particularly with more of the mild losses, and we still get children that are older and are getting hearing losses. Sometimes parents call for themselves. They see a brochure. Sometimes it's health departments. Sometimes it's schools or pediatricians. Also, we have been doing a lot to try to reach out to pediatricians and to -- not just Beginnings, but in our whole early intervention system we have been trying to work hard with the Pediatric Society here in North Carolina to educate them better about resources that are available and what they are.

But most of our -- most of the time we get our referrals from an audiologist. And usually they are associated with the hospital, because we have Duke, we have big research hospital, big huge centers for hearing loss.

LAURA IVERSON: This is Laura Iverson. Are all the parent educators parents of Deaf and hard-of-hearing kids themselves?

DR. JONI ALBERG: No, they are not. Only one is a parent. One of our parent educators is hard of hearing. And the others are either teachers, we have a couple teachers of the Deaf and hard-of-hearing, or they are certified teacher, a couple of them have a certification background in early intervention, maternal and child health background. So there is a variety. When we hire, probably -- as far as what we do for deaf -- real what we are doing is a lot of emotional support, counseling and then linking to services and advocacy. We feel like the most important thing that we look for is the personality of the communicator. Good listener. Compassionate. Those kinds of skills really are critical.

Good communication skills. And the one thing that we -- that all of our parent educator, we drum it in over and over again, is that they are never -- that I would -- that you never hear one of them say, except for the one who is a parent, they never tell parents I understand how you feel. We have been really -- we talked to some parents and had some really good suggestion, and that's like the biggest no that anybody can do, except for Diane. She is allowed to say that, because she has a child that has Collins syndrome and hearing loss and other things. And we don't pretend to know all the answers.

We tell them, if you don't know something, say you don't know, let me find out. So we will. And we will research through our network in the state and link them to answer the question.

So the background isn't as -- the specific background isn't as important as the experiences that they have had. And we really like someone -- they have to have had experience working with families. That is a criteria, that they had some family support roles.

MARY ANN KOWALCZYK: I have a question for Joni, also. Joni, do you have any culturally deaf consultants in your organization?

DR. JONI ALBERG: We do. Our board is required, that's one place, we also have other, too. But the board requirements are that -- I think it's the majority of members of the board have to be parents of deaf or hard-of-hearing, and within that, because we are -- you know, we are considered impartial and we promote all different kinds of communication, we try to have parents who have children who used different communication solutions and have been raised differently, you know, some of them have been raised and are members of the deaf community now, the deaf culture.

So we try hard to make sure that we do keep that integrate D. And clearly when a parent is very interested in that, we have people that we can refer them to. So that is the one area that we really try to make sure. That is the harder one. The other one seems pretty easy.

SUE GREENBERG: This is Sue Greenberg. I had another question for Joni Alberg. I was wondering if you do a special training for your parent educator, if you have a special, I guess, program that you put together for their training?

DR. JONI ALBERG: It's a good question. The simple answer is no, not really. Although we have been in the process now for a little over a year developing a parent educator handbook. But the problem is that it's getting so big, they have to say well, I've got to know this or that. Most of our training is on the job, through the other parent educators. When a new parent educator comes on, first of all they put together their own parent educator notebook that they take out with them to work with parents and the others sort of mentor them in that.

They also don't go out and work with families on their own until they have been out with another parent educator doing home visits, IEP meetings and that kind of thing. It's really a one on one training.

Our goal is to get this handbook developed into something that realistic so we can share that with other states is what we're really interested in doing, which is maybe what you're asking about.

SUE GREENBERG: Yes. It really is what I'm asking.

DR. JONI ALBERG: So we are trying, too. We have this model outside the state, so because we know how great it is and it works so well. And it's a matter of, you know, how do we put all the pieces together so that one can -- we say okay, you've got to do these things and then those get started, and then you can do this next phase and then get it going in your state.

The biggest issue is funding. And it's going to be different everywhere, because every state is organized differently and that kind of thing. But as far as the training and structure and what we provide the parents, that is something that we can put in a concrete format and we're working on that now.

SUE GREENBERG: Good.

MELANIE GAMBLE: I would like to thank all of our speakers for participating in our call. Our next call will be on May 7. We will send out an agenda for that one. And that's our program for today.

