

Help! High School's Almost Over...What's Next?

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Abstract

What do you want to be when you grow up? Will you go to college? What kind of a job would you like? These questions are typically asked of teenagers as they progress through high school and start planning for the future. And it's pretty common for parents to wonder, Will my daughter succeed in college? or Will my son be able to get a good job? Parents of a deaf or hard of hearing teenager may also have additional questions and concerns, and the professional community may not always be sure how to respond. This panel includes a group of parents who have been an integral part in helping their son or daughter consider the options and develop a plan for the future. Each of them has a set of unique experiences related to making decisions, learning about the array of adult services available, and re-tooling their plan, as needed. For professionals, these insights into the parents' experiences will give them a better understanding of how they can be supportive of parents during the transition process, especially during the gradual, but often difficult, process of letting go.



Dianne Brooks: I hope that you are as excited as I am to begin this panel discussion. Yesterday we heard from the wonderful students. It was very inspiring. Several of them came from other countries, and that was really amazing for me because I really had not been around this for a long time. Yet it was an eye-opening experience for me as an individual to sit and listen to those young people's experiences.

We don't want to forget that there are also parents involved in the transition process. They have issues, concerns, and experiences that may be parallel to what the students are going through in the transition process -- transitioning from school to work or to postsecondary education experiences. This morning we are fortunate to have a group of parents who have been through the transition process themselves. They are here to share their experiences with us. Greta Palmberg will facilitate this discussion.

Greta Palmberg: Good morning. We have a hard act to follow. I saw the student panel yesterday and I thought, "Oh, no, here we are." But even as they have their own experiences, we as parents have our own experiences. I think that we are all in a new club. It's called the PODA: Parents of Deaf Adults.

I would like to first introduce the panel and give a brief overview of our sons or daughters and the transition experience that we've had.

My name is Greta Palmberg, and I have a deaf son who is attending the University of Wisconsin in Milwaukee. He is hopefully soon finishing his second year, his sophomore year, and he is studying architecture.

Melody Eubanks: I have a 24-year-old deaf son who attended NTID for three years and has currently been accepted to the bachelor's degree program at RIT for industrial design.

Janis Friend: I am the mother of a 30-year-old deaf son who attended a variety of programs, and I might get into that a little later. He attended NTID, Jacksonville State University, Eastern Kentucky University, and Jefferson Technical College. He is now working for United Parcel Service (UPS) in Louisville, Kentucky.

Sally Prouty: I have a son, Andrew, who is 26 years old, and Andrew is deaf-blind. He will say, "Mom, I can't see very far." We use that term to get the appropriate services. Andrew recently transferred from a job working for the U.S. Army Corps of Engineers, and he now works for the U.S. Fish and Wildlife Service. Just recently in January, he received an award for getting off all government assistance. So Andy is living in his own apartment, commuting back and forth to work, living independently, and is very happy.

Elissa Becker: My daughter is Rose, and she is 29 years old. She graduated from the Lexington School for the Deaf in New York, and from a vocational center for the deaf. She is presently living at home, and she is working.

Greta Palmberg: Well, you now have a brief introduction of our sons and daughters. The proud moms sitting here on the panel didn't get where they were without a lot of effort and without a lot of help. We would like to fill in the story a little bit. I would like each of the panel members to share a little bit about the K-12 years, especially the secondary years. What was your role as a parent on the IEP team, and how did you help the team come through the transition process on planning for your child?

Melody Eubanks: I became involved with the IEP process--actually the first one that my son had--when he was five years old at the pre-school hearing impaired program. I became involved with the deaf educator, the sign language interpreter, the speech therapist, and at some point, some other mainstream teachers. I worked closely with the goals of the current year and on projections for the following year.

Greta Palmberg: As you went through that process, Melody, were there times that were frustrating? Or in that process, did your role as a parent change?

Melody Eubanks: It did. I realized at a very early age at the very first IEP meeting that there were standards that my son was constantly compared to. The teachers would also say that as a deaf person, he probably wouldn't learn to speak higher than a fourth-grade level. There was a constant comparison and then ongoing testing. But I always felt like I was the only one in the room that had high standards for my son. From that day on, I knew that every IEP meeting that I would attend I would have to advocate for my son. I would have to be the one out there gaining the knowledge to see what options could be available for him.

Greta Palmberg: Thank you. Janis?

Janis Friend: Actually, until my son was in high school, the experience with the IEP process was a pleasurable one in that he was in good programs; he was at schools for the deaf. I didn't feel that he

was being compared negatively with the standards. But when we got to high school and he opted to be mainstreamed, this is when some of the struggles began in obtaining appropriate services and working through that transition process. So it wasn't as easy then, but we came through it.

Greta Palmberg: Sally?

Sally Prouty: We were, I guess, fortunate that my husband had a job that enabled to us transfer. So in Andy's first seven years of life, we lived in five states. We were always looking for the optimal education and services and medical services that he needed. We didn't have to battle too much because we felt as though we found excellent services where we ended up in Minnesota.

We did realize, like you have said, that we had very high expectations for Andy. I know that my husband and I would go home and he would say, "Do you really think that can he do that?" And I would say, "You know, I don't care because if I have high expectations, then the people that are working with him will have high expectations, too." I remember times in high school where we were told that the same thing about the expectations, "But your son Andrew already has the highest reading level in this deaf education program." And it was a very well thought out educational program. And we responded, "You know what? We don't care because he still has a long way to go." So it was constant advocacy.

Elissa Becker: I think that the term "constant advocacy" is absolutely correct; it begins from the minute that they are born. As soon as you know what you are facing and what you are dealing with, you need to teach the teachers what they need to be aware of. That's all part of constant advocacy.

The moment when I realized that I had a huge battle to fight was when I realized that the IEP team in my town knew nothing about the deaf and nothing about low-functioning deaf at all. And yet they were the ones who were going to make up her list of what needed to be done in her IEP outline.

Once I really could see clearly that their concerns were not about Ruth, but more about keeping the money in the township and having to use that as the basis for what her needs were, I realized that I had to go out and find all of the programs that she needed to continue to learn as much as she possibly could and not be isolated into a situation where learning was impossible for her.

Greta Palmberg: I think that for myself I had a difficult spot. I have been a deaf/hard-of-hearing teacher on the other side of that table for 20 years. Then I walk into the office as the "mom." I am sure that I may have intimidated some special education teachers when I walked in there. That was not my intent.

But I was a little bit disheartened every time in an IEP meeting to hear what my son couldn't do and also hear what we needed to work on without any acknowledgments about accomplishments he had made and where he was at. I can remember in second grade he was reading at a second-grade level. Why weren't we celebrating that? Because I was quickly told that I can expect him to read at a fourth-grade level. I said, "You have the next, what, 10 years to make him go up two more levels? That's an easy job for you." I wish that statistic could get thrown into the garbage because it just has done more harm than good.

I have battled the expectation at every single IEP meeting. I've been trying to say that until he shows you that he can't keep up with his hearing peers, then that is your expectation for him. And that's where it needs to be. So I was the mom and the coach. Sometimes I was the same as you where I felt like my husband and I left the IEP meeting and we wondered, "Are we the only ones here that have those high expectations?" That was a struggle.

The other thing was listening to our child. At the end of second grade when he was about seven or eight years old, he said to me, "I want to go to the hearing school." And I responded, "Well, you're kind of there."

(Laughter)

"Nope, nope," he said, "I want to ride the bus with everyone in the neighborhood. I want to go to the hearing school."

As a mom I think we always have that second level of fear... that second level of it sounds easy to everybody else.

Just put him in swim class.

Just put him in karate.

Just sign him up for the YMCA class.

What we're thinking in the back of our heads is, "How are we going to get the accommodation? Who is going to say no to us? What if they say they can't afford to pay for those services?" We always have that second level and that's not something that we can separate because we've had that level to deal with for 18 years.

So when they come to a postsecondary place, that's ingrained in us. We're always thinking ahead. What if those services don't work out the way that you promised because, from our history, that has happened before? So let me go to that question.

Can you tell me of a time where there was a frustration in services or an obstacle that your son and daughter or your family had to overcome or had to overcome, and how you did that?

Melody Eubanks: Steven started out in the oral program, and he was there for two years. This was before he was five years old. During the first year he did well, but during the second year he lost more of his hearing and became more profoundly deaf. He was actually severe when he was diagnosed, so the second year didn't do quite as well because his hearing decreased.

At 5 years old he was put into the Clayton County Schools and was introduced to sign language at that point. I think that my defining moment as a mother is he had been developing language from different language activities that we would do with speech. But at five when he learned sign language he was able to come to me and tell me, "Mom, I'm sick and I don't feel good." And for the first time in our lives he was able to communicate that. I was delighted.

He could communicate that through his language, and at that point is when I knew I would have to embrace to learn as much as I could to communicate with him. I taught him to never give up. Never accept no for an answer. And my goals were to persevere through kindness, to work with the teachers, to work with the speech therapist, to merge the two worlds because he was a deaf person who would have to function in the hearing world for his whole life.

I wanted him to grow up and learn this is one world, and we all have to learn to get along together. So through the IEP at an early age I worked with all of the teachers, sign language interpreters. They would poke me in the side and tell me, "Come here. This is what you need to advocate for."

And they had my direct line. You know, we didn't have cell phones back then, but as soon as I got home the teachers would call me, or the bus drivers would call me, or the sign language interpreters

would call me, and they would say, “This is what we need, Melody,” because they knew I was part of their team. Our goal was to achieve that goal for our son.

Janis Friend: Wow. I am going to try to not get on my soap box here. This is going way back. When my son was first diagnosed as being profoundly deaf, he was about a year old. I had never met a deaf person.

When someone came to me and said, “We have just the program for your child and we can make him just like a hearing person.” I said, “Oh this is great!” so we put him in the program. He was there for 3½ years, and it was called Verbal-Tonal. Remember, this is a profoundly deaf child who struggled for 3½ years and was saying, “Ba, ba, ba, ma, ma, ma,” and that was about it. He was becoming increasingly frustrated.

We had no communication. Our communication when he wanted something was to go in the kitchen and stand and scream while I emptied the cabinets or the refrigerator or whatever he was screaming in front of until we found what he wanted. And then he stopped screaming.

So at five years of age he was kicked out of the verbal tonal program because his behavior was so bad.

(Laughter)

Imagine that. No communication, five years old. I can get really, really bitter about wasting all of those language development years. I try not to do that. But as hearing parents we're at the mercy of the philosophy of the program that diagnoses our child as deaf. I hope that's changed. But regardless, he was kicked out of that program.

We were living in Knoxville, Tennessee, and he was referred to the Tennessee School for the Deaf. He started learning sign language, and it was like 360 degrees. This kid took off. I started learning sign language at the time he learned sign language. But could I keep up with him? Never in 1,000 years because it was just a whole different world. And became, I think, a model child.

(Laughter)

Greta Palmberg: They all are.

(Laughter)

Janis Friend: My husband was in management for Nationwide--that big tower across the street--and we were transfer several times. We moved to Kentucky to live close to a school for the deaf. When we lived in Memphis, they had an incredibly great day program with over 300 deaf students in it.

So we were very fortunate that we moved back to Louisville which was too far for him to be a day student at the School for the Deaf. He had always been a day student. This was an assumption that I made that he would go back to the school for the deaf and live in the dorm or whatever.

And he said, “No. I want to be mainstreamed.” So that was when our battles began, and it was a struggle then for the next four years. But it was his decision. I received a lot of flak from the Deaf community because I was also a professional in deafness, but it's his decision and we'll deal with it.

Greta Palmberg: Sally, what about you? Was there a defining moment that you can think of for your family in Andrew's adventure and transition?

Sally Prouty: I think many parents feel as though, “Okay, we've got this IEP. We're going to be on this IEP until hopefully 21. We'll take advantage of all of the services, and then we're done. And then our job is over.”

Well, I think that the defining moment for our family was realizing that we are lifelong advocates for our son, Andrew, and I think most of us will agree with that. I have two other children who are now young adults, and, yes, I am an advocate for them. But it's a lot different having a child who is deaf-blind.

Elissa Becker: I think my defining moment for Ruth was when she was out of the Lexington School, and nobody told me what to do. And it was the first time that I was not prepared to tell somebody else what to do. So it took a very long time for me to research and find help through the adult services.

What I found was, because she was not only deaf but also severely learning disabled, that was going to be something that people just didn't know how to deal with at that particular time. So I had to go to the mental health offices and try to get help from them, along with vocational rehabilitation in the State of New Jersey. However, they didn't talk to each other, and so it became my job to be messenger between the two and get services done between the two different organizations.

It took over a year, at which time Ruth was just sort of sitting there until I met a lovely man who is part of the Lexington Center in New Jersey who said, "Wait a minute, we can help you because we will go out of our way to find Ruth employment and we will support her needs with a job coach interpreter."

It was at that moment that I realized that there were people out there who really cared, and there were services except that nobody told you about them. So it became my job to make sure that everything that happened with Ruth was marked down so that I could model it no matter where we were. That was probably the turning point in her life as well as mine.

Greta Palmberg: We all have different defining moments. I think that for my family, it came very early. I was a special education teacher before I had my first child. So I was in the world of learning disabilities, and emotional behavioral disorders. In the learning disability world, our philosophy was “whatever works.” We tried this, we tried that, we tried this, we tried that. Some of it worked for one child. Some of it worked for another. And the goal was to make progress. Whatever you could find that would make progress is what you used.

And then I had my son. At seven months old I found out he was deaf. As an educator I was shocked that nobody agreed on the communication system I should use as a parent, on the education system I should use as a parent, or on the medical treatments, if there was one to use. As a parent, I was placed and thrown in a battle. But my heart was about this little baby, the seven-month-old baby that I felt I was not connected with. And I had to find a way to connect with my baby.

We finally decided that I was going to do signing. I won't say ASL because that didn't happen until many, many years later, and I am still learning. But we were going to sign. I remember carrying this baby around the house pointing out things in the kitchen and the living room and signing. I had this little parrot with these little hands that would sign back to me.

The first sign was cookie, and I am looking in my dictionary, “What was that, what was that?” And it was cookie. And we were so happy. And then it was “mom.” Notice, before “dad,” it was “mom.”

(Laughter)

So and then of course it was “mom” and then “dad.”

(Laughter)

And so we went around to the parent class and saying, “Oh, he is speaking ‘mom’ and ‘dad’.” We’re so excited.

(Laughter)

Until the sign language interpreter told us what that was.

(Laughter)

And then my husband wasn't too happy.

(Laughter)

But I still felt a disconnect from this little baby. I felt like who is this person in here? How can I connect? And I was just getting back everything. And my hands, I'm like, am I communicating? It was just so foreign to me.

When he was about 12 months old, I was driving in the car. At that time you could have the car seat in the front seat, so he was in the front. We were at a stoplight, and like all young little boys he was just enamored with trucks and cars and all of those kinds of things. While we're at the stoplight, he turns, looks at the gas station, and sees a car coming out of the car wash. He turns to me and he signs, "Mom, car cry." And that was my defining moment. I thought, “Okay, I know who you are. We can have a relationship we can communicate. This thing is working.”

(Laughter)

Keep doing it.

We all have those defining moments. I think what I didn't realize was the battles. I hate to call it a battle, but we go to battle for our sons and our daughters. We see them invited to birthday parties where we know they can't communicate with anybody at the birthday party. Do you send them there and let them be frustrated? Do you keep them home? Do you ask the neighbor if you can send an interpreter with them? You know, everything, everything that they do in their life is not easy. And that's part of our life. It becomes our life.

As we leave the secondary system and we go to the adult world, sometimes people don't tell us that the game just changed and the rules are different. And we have been there. We've been the advocates. We've been helping. And now the rules are different. We don't need you anymore. They're 18.

(Laughter)

Do you know my 18-year-old?

(Laughter)

I want to talk with the panel because here we have a lot of postsecondary, vocational rehabilitation and community rehabilitation people. What was that shift like from the school system to the adult world? How did your role change and how did you figure that out?

Melody Eubanks: Through trial and error and a lot of bumps and bruises along the way. The State of Georgia initiated a high school graduation test. When my son was in his junior year, I was told that he would have to pass all of the portions of it in order to get a regular high school diploma. He started taking the tests in his junior year, and he passed the math, science, and history. By the time he got to his last portion of the senior year, he did not pass the writing portion of the high school graduation test. I was told although he had a 3.8 GPA and had gone through the four years on honor roll, he could only get a certificate of completion. That was when my gears kicked in again, I guess my motherly instincts.

I was like, “My son fought four years to maintain a high GPA. He was a pretty good student, never had any problems with educational system, and you are telling me that he can only have a certificate of completion? Fine!”

So I told Steven. I said, “This is the bureaucratic stuff that we have to go through. We're going to get you through high school, and we're going to get out, and we're going to do what has to be done for you to excel.”

At that point that's when we found out about a reading and writing course that was offered at Georgia Perimeter College in Atlanta taught by Katherine Bruni. We decided to send Steven there because we told him, “You didn't pass the writing portion of the Georgia high school graduation test, but you will.” He knew in our home it wasn't an option. If he failed he picked himself back up and he carried on. And that's the attitude he's always given.

Part of the learning process is learning how to teach him to be an advocate for himself. So he got a tutor. He had a private tutor and he attended that class. He also went to the Georgia Council for the Hearing Impaired and got tutored there through a GED program. So he had like three different things he was trying.

It took him two years. During this time that he was attempting to pass the writing portion, he was there every time trying to pass it. And we had applied for a waiver request through the Georgia State Board of Education. We waited approximately one year. I kept calling, “Can you tell me the status?” The response: “Well, it will be presented at the next board meeting. It's a long process, and you will have to wait. And do you realize that there never has been a waiver granted?” And I was like, “I understand.” Like I said, my motto was always perseverance through kindness.

So we waited, and approximately one year to the day I called that office, and the lady was puzzled that I had called. She said, “You didn't hear?” And I said, “Hear what?” She said, “Your son passed.”

It was his 13th try. It saddens me to sit here today to say that my son was drug through, and his self-esteem was diminished. But we gave him no option.

I failed to mention that he had visited NTID. They said, “We'll look at the whole picture and consider what kind of diploma you will get from high school, and you may be able to get accepted.” Well, lo and behold during this process we found out, that you need a regular high school diploma. So I told him at that point, “Steven, you're going to pass this writing test.” I told Katherine about our struggles. Katherine said “We're going to get him through it and he is going to pass it.” So on the 13th try, after two years of trying, my son never gave up.

Sometimes he would get the results two months after he took it, and he would come home and he wouldn't even tell me. I anguished and I hurt for him that he had to be drug through what I call

bureaucratic guidelines that were set up for this testing system; he was somebody being tested in English as his second language. But he did not give up, and he is at NTID. I have sent letters to the State Board of Education, and informed everybody about his continued success.

(Laughter)

He is at RIT. He is very independent. In fact, when he was at NTID for three years, he told me, "Mom, I'm going to RIT." And I was like, "Sure, son, okay."

(Laughter)

Sure enough, they wrote us and they told us that he was accepted in the bachelor degree program for industrial design. He never once came to me and said, "Mom, help me with my portfolio, and what am I going to do?" He did this all himself. And he is at RIT now.

(Applause)

Janis Friend: I am sitting here listening and I am amazed how similar this is to an experience that we had in Jefferson County Schools in Louisville, Kentucky. There were a couple of really, really tough moments.

First of all, when we moved to Louisville and we asked for him to be mainstreamed, they had never had a deaf student mainstreamed with a full-time sign language interpreter. He was the first, but they agreed and we moved on from there. But they did ask that he be mainstreamed in the same school where they had the program for deaf students. They didn't feel secure with him there without that backup.

For the first year he was in that school which was downtown, it took him an hour to an hour and a half from our home on the bus to get downtown and back. So his next year he asked to be mainstreamed in his neighborhood high school. I can tell you that I was a wreck before we went to that IEP meeting to make that request. I didn't sleep all weekend. I called a lawyer. I mean, we were prepared. My husband and I went out to lunch and discussed it and discussed it and just agonized. And when I say agony, yes, it was agony.

My husband got the idea of taking a tape recorder to the IEP meeting because he wanted to make sure that everything was documented in case we had to file a lawsuit or something. So we walked in and he said, "I hope you don't mind if I tape this meeting." He set the tape recorder down in the middle of the table, and everybody is like (indicating). Now, I know that IEP meetings can be intimidating. And, even as a parent, an educated parent, I was intimidated at IEP meetings, even though I attended them on the other side. It's very different.

I can just imagine how parents who don't have a lot of educational background feel when they walk in that room with table full of professionals, and we know it all. We know what's best for your child, even though as parents, we know our child better than anyone does. But we got through that. They agreed, and then he had the interpreter.

He was making "As" "Bs," and he may have had a "C" thrown in there once or twice. He got through his junior year and the school said, "By the way, we've implemented a mastery test he has to pass to get his diploma." And I'm like, "No, no, no. You are not telling me that he has worked this hard and made his grades for all of this time, and whether he gets a diploma or not will depend on passing an English as a second language test."

They were only allowed to take it three times. He took it once in his junior year and passed math the first time. He could not pass the reading comprehension test. They offered free summer school

if you didn't pass it as a junior. He went to summer school, took it again, and didn't pass the reading comprehension. And so I started writing letters and calling people and telling them how discriminatory this test was, and nobody would talk to me. Finally I got a letter from the man who was the head of testing for Jefferson County Schools, and he said, "Well, we will allow accommodations for the test. He still has to pass it but we'll allow the test to be interpreted."

I called the lady who was head of deaf education at that time, and I said, "I want an interpreter for my son to take the test. I want the test interpreted." And she is like, "No, you can't do that. Only the instructions can be interpreted." And I said, "I have a letter here from Dr. Romney, and it says..." She responded, "Let me go get my copy." When she came back, she said, "You are right. It does say that," and I said, "Yes." She said, "Well, we'll let his classroom interpreter interpret it for him." I said, "Uh-uh, because his classroom interpreter was not a certified interpreter." It's the law now, but it wasn't then. Some of you may know Norma Lewis who is one of the world's greatest interpreters, so I said, "I want Norma Lewis to interpret the test."

(Laughter)

And they said, "Oh. Well, if we have it interpreted for Rob, we have to do it for all of the deaf students." And I said, "Yes."

(Laughter)

The school representative said, "Well, how will we do that because they're all down at this high school and he is out there?" I said, "He'll drive downtown."

Norma told me that the first day he came in, he was white as a sheet. She said that she feared he was going to have a stroke or a heart attack or something. It's terrible to do that to a child --put that kind of pressure on them that they've worked and worked and worked, and then you are saying you've got to pass this little test before you can get your diploma.

So I related to everything that you said. But I guess those are two of the toughest things. He did pass it with Norma's interpreting the test, and she said that at one point the special education or deaf education coordinator came in, and she said, "I don't even want to know what's going on in here. And she left.

(Laughter)

But we got through it.

Greta Palmberg: Thank you, Janis. Sally, could you talk about the adult services and how that change came along?

Sally Prouty: You know when you have a child in special education, it's like -- well, I felt in Minnesota that we got the Cadillac. The kids get everything. They have a bus that comes to the front door and it waits. It doesn't just stop there while the kid waits. The bus waits. So we get kind of spoiled because so many things are provided.

In Andy's IEP meetings we sometimes would have 12 people around the table, and they all had Andy's best interest in mind...and then comes graduation. He did go through a wonderful transition program with Greta as his IEP manager. But when that ended, suddenly I was no longer an integral part of the team anymore. I mean, starting at age 14, Andy started coming to his IEP meetings. By the time he was a senior in high school he started running; and by the time Greta got a hold of him, he was running the meeting with a lot of assistance from her. So he was on his path to becoming more independent.

But then get out into the real world and people don't talk to the parents anymore. They talk to the kids. It's a helpless feeling. I can give you one example. Andy finished the program. He was bound and determined to be a designer. He was going to make the games that Nintendo uses. He wrote a letter to Nintendo of America in Washington, and this lovely woman wrote him a private two-page letter, a personal two-page letter back to him describing how rigorous the program was. Lots of math...lots of high-level math. She suggested that maybe he start taking a class in computer design and see if he liked that, and then he could consider going on.

So he takes the class, he signs up, he goes to the disability office. And remember I said he's deaf and he just can't see very far? Okay. So he neglects to tell the disability office that he has very low vision.

So here is Andy in this class. He has an interpreter, which is, you know, to be expected. But he didn't not provide information that he couldn't see very well. This is a computer class, so the instructor is demonstrating on a computer monitor. Well, guess where Andy is sitting? Right in front of that computer monitor, and none of the kids around him could see. And he is oblivious. And nobody says anything to him.

I don't know if it's this poor deaf-blind kid that nobody wanted to bother, but nobody said anything to him. So he gets a message from the disability coordinator and someone further up; he forwarded it on to me and he said there is a meeting. I said, "Andy, what do you think the meeting is about?" He said, "Oh, I think it's about I asked them to get a note-taker." I knew that wasn't going to be the case. I didn't know what was going on because to no one talked to me. I am just the mom.

So we get to the meeting and they just dumped on Andy about how inappropriate it was. I mean, this was not the time and the place. The time and the place was taking him out after the class and discussing with him that maybe he should have told them about his vision loss. But no, it came to this very end where he is humiliated. And that point was my defining moment that I will always be involved somehow. So, yes, it was a learning experience for him, but at a very high price.

We get spoiled as parents having an IEP meeting with 12 people around and everyone looking at the parent because we have all of the background information. But then you get to adult services and we're gone from the picture. How have we handled this? I shouldn't say that he doesn't depend on us. He is very independent. He is very open with us. He does come to us for advice. I guess we're just playing the game and if something comes up, he'll run it past us. We will discuss it, talk it over, and then goes back and present a solution. It's basically our voice, but he is presenting it. That's the way we've handled thing.

Elissa Becker: Your story about the recorder going on the table in the middle of an IEP meeting brought back fond memories for me. It was about the same story, but that's not the question right now. So I will tell you that one later.

Anyhow, I think a very defining moment for us, Ruth and I, was after Ruth had completed her program at the Hiram G. Andrews Center (HGA), and we moved to Westchester, Pennsylvania, because Lori Hutchison said that's where you have to live, and I said okay. I had no idea where Westchester, Pennsylvania, was, but it did turn out to be a sweet town. We hoped that it had all of the services that Ruth would need after graduating from the most wonderful experience of her life. We were there, and lo and behold, we're told that we now have to contact the Office of Vocational Rehabilitation (OVR), and they will help Ruth find a job.

Well, the defining moment came when the people from OVR said, “Oh, okay. We don't know what she can do, and we're not sure if we have any placements for her, nor do we have any coaches that will be signing.” When all of this was presented to me, I said, “Okay. I think we have a problem here.”

Because of the model experience that I saw in New Jersey with a job coach, and because of that same model I saw going on at HGA, I found people that I would hire on my own and train them. That was how we moved forward, so that Ruth would have a reason to get up every morning and fulfill her need to be part of her community, and that's what we do.

We just sort of manage around the situation because truly the services that we've been offered in Chester County fall short of what I know should be because of my past experiences, and I know it's perhaps because of the fact that Ruth is also developmentally delayed and learning disabled that the OVR doesn't have the support team that we need. But we've gotten past it, and I am hoping that there will be more people in Chester County who can be serviced with all of their needs based on the fact that many telling this story.

Greta Palmberg: I will just add that you are starting a foundation in your daughter's name for support services

Elissa Becker: I started it about four years ago, but because of the terrible situation in our country, the federal government is very careful of who they allow who can become a 501(c)(3) corporation. I don't think that I look that tough, but it did take four years. Finally a year ago we got our certification from the federal government, and we are registered as the Ruth Becker Foundation for Deaf Support.

Our mission is to provide services in and around our community. That's where we would like to start. We'd like to offer these services to people very similar to Ruth with her needs as far as being profoundly deaf, deaf disabled, learning disabled, all of those things that don't stop a person from wanting to be part of their community. It doesn't stop a person from saying, what did I do today? How exciting--tomorrow I'm going to work.

It's important to give them sustained support, not 90 days which is almost impossible, but a sustained support for a longer period of time based on the fact that most of these clients also have the support of MHMR who have utterly no services for the deaf. So this would be a way to connect all of that and help these adults find a mission and enjoy going to work and succeeding. The end result is success.

Greta Palmberg: Janis, this is also a passion of yours.

Janis Friend: Yes, it is. I am just appalled when I hear that these service do not exist, because I work for Vocational Rehabilitation, and Ruth is the kind of individual that we are set up to serve. So I would like to invite you and Ruth to come to Kentucky, Just move to Kentucky and bring your foundation.

(Laughter)

Elissa Becker: Yes. You're bourbon country.

Janis Friend: That's right. I am right in the middle of it.

(Laughter)

Greta Palmberg: We've got a few more minutes, and I have one big question for the rest of you. My son went right from high school into the postsecondary setting, I think that I want to address that just for a moment.

Being a teacher I hope that I'm giving my son all of the self-advocacy skills that he needs at 17 and 18 to join the college setting. I tried the best I could, but he still is an 18-year-old, and if you have an 18-year-old they know everything and you can't tell them a thing. And they don't know what they don't know. But they know it all.

(Laughter)

That was a little scary for me. I was also scared to be labeled a "helicopter parent," and I have worked in my profession with helicopter parents, so I know what they look like, and I can feel the hover coming.

(Laughter)

I hope that none of the University of Wisconsin staff think I am a helicopter mom, which I don't think I am. But when my son got into college, I thought he had self-advocacy skills. I had no idea the level of self-advocacy skills that he would need on a big university campus. No idea.

Socially and emotionally, I don't think that I could have made him any more ready than he was. He did understand disability services and what he had to do there. He did not understand other places of the campus where he needed to go to other people. So when we arrived in his dorm room, as proud parents we helped to get him all set up in his dorm and we noticed a box that says "hearing impairments" on the bed. We open it up, and it's a TTY. It's like, okay, whatever.

(Laughter)

And so as the mom, I am just kind of suggesting to now this 18-year-old young man, "Hmmm, what's going to happen when your friends come by your dorm room? How are you going to know they're there?" In his brilliance he says, "I will leave my door open all the time."

(Laughter)

Like that's going to work for you.

We noticed that the fire alarm was outside the hallway. So as soon as he closed his door, the lighted fire alarm was gone. "Who are you going to ask about this? This is not working for you. Where are you going to go?" I asked. So he is at college and so excited to be there, and I am still self-advocacy teaching here. "Where are you going to go for this? What are you going to do for that?" He has done remarkably well, but there are things like that that come up all the time.

My last question to the panel, because I know our time is running out, is what suggestions or advice would you give to either families or to adult services? What are your little words of wisdom?

I guess I will start.

For the postsecondary setting, my words of wisdom would be as a parent, I feel it's my last chance when I come visit your colleges or call on the phone to ask about your services. That's my last chance, and then I get cut off. So if you could just not put on your blinders, "Oh, no, here comes a helicopter parent," and listen to some of the things that I am saying, because some of the things I am saying you are not going to hear from the student until they're failing. And if you would have just maybe listened and jotted a note down you would have known to catch up.

I think as a parent what I wanted to hear was at this college or university, “Here's our safety net. This is what we're going to do,” whether it's, “We're going to watch their grades at midterm first quarter, not that we're going to let you know what they are, but we're going to follow up with your child if we see that things are not going right. We are going to send them e-mails to remind them to come to the disability service office.”

So if I know what your process is, I'm the coach now on the sidelines. I had to do this with my son. I know he just registered for classes, so I am paging him, “Did you go to the disability service? Did you tell them what you need?” and I can be an advocate that way. But if I knew how your system worked and what was required of him, I could help more behind the scenes. That's my suggestion.

Melody Eubanks: When my son went to NTID, he started cutting the umbilical cord early, and he knew I was a helicopter parent. I landed when he was first born.

(Laughter)

He is just like his father, and God gave him the exact personality he needed. But when he went to NTID, he forced me to go to NTID. I thought, “You'll be fine at the community college in Georgia, come on.” And he said, “No, mom. I want to go to New York and visit.”

So early in his first experience at NTID, he started weeding us out. During the first three years we went and visited, stayed on campus online, finding out what he did, and kept up with him on the sidelines. I wanted to respect his independence. I wanted to respect the code of ethics that certain professionals have to follow. So it was easy because of the Internet to keep up with him and to reserve that respect for him.

But we asked questions and contacted his counselor once or twice. I remember the first year he came home, he lost 20 pounds. And I said, “You've got to go to the doctor. We've got to see what's wrong.” Anyway, the doctor finally contacted me and said, “He is fine. He is just homesick. He is more worried about homework and socializing. He forgot about eating.” But he is doing fine, and he has cut the umbilical cord and is learning how to stay focused. Be informed about the curriculum out there and the services. I've always told him even when he jumped from high school to college, if you need help, if you need tutoring, if you need note-takers, or if you need interpreters, ask. The services are out there. Grab them. Thank God he is in an environment that has the whole world opened up to him.

But you have to respect the teachers rather than creating animosity between the professionals; it's a learning experience for them. I used to think, “Well, they're on the other side of the podium and they know exactly what my child needs.” But they don't. You soon find that out. And if you don't, then you are not doing your homework as a parent. You have to become informed. You have to know what's out there. Then you together with that team, regardless if it's K-12 or postsecondary, make that informed decision together. It's very important that you promote independence for your child.

Janis Friend: I'm trying to think back that far. My son is a little older, and you mentioned texting. We didn't have that.

Greta Palmberg: It's a great thing!

Janis Friend: I know. We didn't have e-mail when he started college. We didn't have texting, and thinking back to when he turned 18, he was still in high school. I do remember the first time that

somebody said something about Rob having an IEP meeting, and I was puzzled because I didn't get any information. And they said, "No, you wouldn't. He is 18." I had been going to IEP meetings since he was five years old, and they said, "He has to invite you, and he has to give us permission to share information."

Now, I had always pretty much been Rob's contact with the world because we communicated, so I was used to being a very integral part of his life. But I will never forget when he went to NTID that first day. We left him there. My husband and I drove off, and I can see him standing there on the sidewalk. And I cried all the way home. I mean, it's like this is my baby. He is there. He is alone. Does he know what to do? Will someone help him? Somehow he did.

He got what he needed while he was there, but I know that one struggle that he had was being mainstreamed in the '80s. He totally missed the deaf culture movement. When you have a deaf child going to a program for the deaf in a postsecondary setting like NTID or Gallaudet University, that can be pretty tough. He had some really tough struggles.

Weeks went by and I didn't hear from him. We didn't have text messaging. I was a rehabilitation counselor for the deaf at the time in Louisville, and I was frantic. I was just totally frantic. Linda is sitting here smiling at me. She knows my son. Finally I called someone I knew at administration at NTID and I said, "I haven't heard from my son in two weeks. I have no clue what's going on. I am going crazy." So she went down to his class, got him out of class, and said, "Come to my office and call your mother."

(Laughter)

Talk about a helicopter parent.

I said, "Son, why haven't you called me? What's going on?" He said, "I've been busy and having fun."

(Laughter)

So I knew he could get along without me.

Greta Palmberg: All parents feel that nervousness when they drop their son or daughter off at college. I do think that we have an extra level of nervousness.

I remember when we dropped my son off. We were taking him to the bookstore, and I lost him in the hallway. Age 18 just found him and all of a sudden he is signing to all of these girls. And I'm thinking, "Okay, looks good."

(Laughter)

Then you do the parent thing. You take him out to dinner, the last supper.

(Laughter)

So you take him out to dinner, you bring him home. Back at the dorm room there are three notes on his door from three girls in interpreter training with their room numbers and phone numbers.

(Laughter)

E-mail addresses. I looked at my husband and said, "We can go now."

(Laughter)

Sally Prouty: When Andy was born, he was fortunate that he got his diagnosis of being deaf-blind, right away. He was just under a month old. It wasn't so fortunate for us. It was really hard, but we won't get into that. We're talking about the other end.

My husband and I educated ourselves. We learned. We became involved in the deaf community. We belong to a deaf church. I went through an interpreter training program. We got to know adults who were deaf. We got to adults who were blind. We got to know adults who were deaf-blind.

Although we met very many successful people, there was also the population who didn't work, and who lived on SSI. We were bound and determined that this was not going to be Andrew's path. We just looked at an old videotape. We were interviewed when we lived in Oregon. Andy was a baby, and we said that he would be a tax-paying citizen. We didn't know what was between what happened then and where he is now, but that was always our goal.

So my advice to give new parents is that it's never too early. At age 14 when they started saying it was time for transition, I thought, "Oh, my gosh. He is only 14 years old." It could have been started earlier.

So what we started doing with Andy and all of our kids is that we gave them chores. Along with chores came money, just like a job would provide money. Then by the time Andy was in high school he wanted a part-time job. He wanted to earn some money. So we immediately went to our rehabilitation agency, and we said, "He would like to work." And they said, "Okay." Well, that was our cue that whatever is going to happen is going to be from us. So we were instrumental in finding Andy his first job.

He wanted to be a baker. He loved baking chocolate chip cookies, and he was going to be a baker, by golly. We walked into our bakery and the sign said "Help Wanted." We talked to Andy about it. He said, "Let's go." He went in to interview, and they hired him. It wasn't for a baking job but it was as a dishwasher. But it was a start. He got his foot in the door, he made money with hopes of becoming a baker. There were two owners of the bakery, and she had a sign language book and she was awesome. The other partner worked at night and did the baking. We thought, "He doesn't have to deal with the public, it's just the two of them, and they can bake their hearts out all night." But we got this kind of hesitancy. Finally we said to the other partner, "Mariah, what's going on?" She said, "You know what? My partner is concerned about communicating with Andy." We said, "It's not a big deal. There's not going to be a lot of communication. They can just write back and forth." And she said, "Well, that's good for Andy, but you know what? My partner is illiterate." Now, what's the likelihood of that?

(Laughter)

So he decided, "All right, I am not going to be a baker, I have to find something else."

The next job was another job that, again, was connections that the parent made. Our assumption was going into this like into the IEP world of school people are going to help you and do things for you. We thought people would bring Andy jobs. That just isn't the case. I would encourage all parents to use whatever connections they have in the community because you are the connection.

Andy's next job was from a neighbor who had a sister who I think is 55 now, and she was a preemie. The doctor out on the farm in Iowa sent her home in a shoe box thinking that she was going to die. Well, she didn't die. She grew up and she was deaf-blind. Our neighbor said to us, "I want to give Andy the break that my sister never had." It was our connection with that person that made that happen.

So my advice would be that it's full-time advocacy. My motto has always been "Be respectfully demanding."

Elissa Becker: Coming from New York, I say, "Be demanding."
(Laughter)

Sally Prouty: We have a term in Minnesota and it's called, "Be Minnesota nice."
(Laughter)

Elissa Becker: I think that my advice to parents would be to listen to your child. With someone like Ruth who needs continuing support, listen to what they're asking. Then go out and help them find it. They have the answers to what they need, and that's another success for them.

Just getting the right answers and knowing people are listening to them is important, even though it comes through another mode called "mom" or "brother" or "cousin." It really doesn't matter. Just get them out there and let them ask. Help them get their answers.

Greta Palmberg: Well, I just feel honored to be sitting on this panel with these other women who brought their children to a level of success that maybe others never thought they could attain, and with the help of wonderful support services. All of you women are doing things now in your career life to help other deaf and deaf-blind individuals meet their success. That says a lot about you.

Because I am a teacher and I sat on the other side of the IEP table, I think my experience changed the way I sat at that table. I always thought about the parent. What information did they need to know for empowerment? Did they understand everything? Should I slow down? Should I describe all those terms that I am throwing out that I'm used to saying? They have no idea what I mean when I say "community rehabilitation" or "vocational rehabilitation" because they don't even know what those are.

I guess my suggestion is for those parents who have trouble or are not advocating, it's our job as service providers to give them the information to empower them to help their deaf and hard-of-hearing and deaf-blind sons and daughters achieve what they can.

At this point we've got about 15 more minutes to go, and I would like to open it up for questions from the audience. If you have any questions you would like to ask of the panel, please remember to come up and use the microphone or stand up here and sign. So do we have any questions from the audience?

Audience member: Good morning, everybody. My name is Tom Dean, and I am originally from Cincinnati, Ohio, but I live and work in Louisiana now. Hearing you all speak reminded me of my own transition story way back when, when I first left Ohio, went to New Orleans to go to college. I'm hard-of-hearing. I grew up hard-of-hearing, I am hard-of-hearing now, went to all hearing schools, but I guess I give you the story from the flip-side. My mother and I drove down to New Orleans from Cincinnati. She dropped me off for college there. And I had to take her back to the Greyhound bus stop for the long ride back to Cincinnati. I guess it was when I knew them that the umbilical cord was really cut. I just want you to know that it's not only bittersweet for the parents, but it's bittersweet for the students as well. Thank you.

Audience member: I have a question from another point of view. I know that it's not any kind of situation where the interpreter would be in the position to be pitied, but as an interpreter and in

working with deaf students at a college and meeting their parents, there are many times when the deaf student will ask me, “What did she say,” or “What did he say,” because their parents don't sign. Of course, I know that in most cases, in many cases, the parents and child have very loving and close relationships, and that the parents feel a real connection with their children. But as an interpreter, I feel a little intimidated in that situation. I feel a little uncomfortable, but I'm not going to tell them how to run their lives. Have you ever seen that, and what advice do you have for the interpreter?

Panelist: Thank you. That's a great question. I work in a transition program for 18-21, and we work with a lot of refugee families. Maybe they didn't learn sign language in their native country for their child and their child didn't learn it there either. So they come to America, and they have other children, and they're trying to fit into the American culture. At our IEP meetings, it's the only time where we have maybe a Somalian interpreter, or a Hmong interpreter, and a sign language interpreter.

For me as a teacher and a mom, the parent never gets this communication set up at other times. So there are times when families have family issues to discuss and we will extend the IEP meeting. Everybody will leave and let all of the interpreters stay so that family can have a discussion that's not afforded to them any time else. Is it the perfect situation? No, but I'd rather give them a time to communicate than not at all. So I understand the awkwardness of being in that situation as an interpreter, but those are golden moments for families, and I thank you for being a part of that.

Audience member: I would just like to say that I loved your presentation, and the love for your children just came through. But I think that it's parents of middle school people who need to hear your message of today. I think that it would be a great idea if PEPNet could somehow - even though they're funded for college-level services - took this and turned it into a CD or a DVD and middle school parents could hear it. Thank you.

Panelist: I think that would be our advice to all. Start early! We didn't start early enough.

Audience member: First of all, I would like to thank each and every one of you for sharing your stories with us this morning. As a parent, I have been a very untraditional male in that I have been extremely hands-on in raising my son. I would like to know what part or role your husbands played in this process, if you could share that with us. Thank you.

Panelist: I would like to tell a funny story about my husband. My son is just like my husband, thank God. They knew he didn't need my emotional side. When my son was about six years old, my husband and I were tired of hearing, “No, no, no.” We wanted our son to grow up and experience the normal things of the hearing world. My husband signs, but he doesn't sign as proficient as I do, if you can call mine proficient.

But anyway at six years old they both came in, and my son said, “Mom, I signed up for baseball.” And I looked at my husband, and I had this look on my face like a deer caught in the headlights. “You did what?” I asked.

He said, “We signed up for baseball.” He was signing to me. “We signed up for baseball, Mama, and I start on Saturday.”

So I took my husband aside and I said, “Well, did you tell them he is deaf?” And he said, “No, why should I?”

Wow, that was a light bulb moment for me. It finally came on. Why should that hinder him?

So at that point my husband jumped right in. He said, "I am going to become assistant coach." And everybody loved him. I'll never forget this: At one point one of the coaches said to us, "I wish sometimes that all of my other players were deaf because they didn't have to be focused on."

(Laughter)

My husband was the breadwinner; we married young, at 21, and had a family, and we had big dreams. When Steven was born deaf, a boomerang was thrown in it. But my husband always had to be the one that worked. He went to college, worked third shift, lost a lot of sleep, but he was there. He was the support. He was the backbone of the family. I was the one doing the things, but he was the one to do this. He needs this. He was the silent, strong partner and continues to support us today and has given my son his attitude that don't give up. They tell you no; you find the yes.

Panelist: My husband was also very involved, and he learned to sign. He didn't sign as proficiently as I did because he wasn't around Rob as much. I was a stay-at-home mom when Rob was growing up when he was young. But they had a very, very close, very loving relationship. My husband was always there, and they did things when and if as they could together. My husband passed away this past fall, and it's been very, very, very tough for my son because he just idolized his father. They just had such a close relationship. So that's a big gap in his life right now. But he was very, very involved and very important to my son.

Panelist: I had the luxury of staying home with the kids, so, of course, I was more involved. My husband... I couldn't do what I do without him. He is my rock of Gibraltar. He has hired employees who are deaf so his signing skills have improved. But, again, he is not around it as much as I am. So, yeah, he has been involved.

Panelist: My husband is a techie, and I am a teacher. So we divided and conquered. He has kept up with all of the latest technology. When the Sidekick came out, I don't know if my son could text, but he had one. We've got the closed captioned hooked up on the TV, learned how to use the TTY, the computer is all set, hearing aids, that was his piece. So each of us took a piece and it worked out as a team that way.

Audience member: Thank you. My compliments to Greta and the panelists for a whole host of magical moments and a great conference. My question is for systems relationships and systems change. I am glad to hear that about FERPA, but we know that there are often gaps in what's desired, what's planned for, and what the systems -- vocational rehabilitation and postsecondary education -- can provide.

So this question is similar to what I asked the younger people yesterday: If you could change one thing, if you had magic to change one thing about systems in the relationships, what would you change?

Panelist: The only system I am familiar with is the vocational rehabilitation system. But if I could change anything that would better service the needs of the deaf people today, it would be where everybody from a professional viewpoint or standpoint -- a teacher, sign language interpreter, a speech therapist, a bus driver, those that are in constant contact with our kids -- are familiar, and they know their needs. They see their individual needs.

Because of bureaucratic guidelines and rules that are put in place, they are limited by their own code of ethics to go and spread this is what the kids need today. I had people come to me today to

say, “We need you advocate for the Georgia high school graduation test, the instructions to be, you know, interpreted.” I had to go out and petition, but I couldn't reveal to them and publicly thank the person who told me because it was against the code of ethics for them to speak for the deaf child.

I am so grateful that I was able to have that open opportunity, that open door with professionals, and they knew I was a parent there for my child. But I wasn't just there for Steven. I was there for them. I was there to help them facilitate their career and deaf education. They all knew my child better.

So if I could change anything, I would open the doors for proper communication to facilitate the needs of the deaf children and make it all right for everybody to communicate and not be threatened that they would lose their job.

Panelist: I would hope if I could do something that's really magical, I would love to see a joint meeting between MHMR, OVR, and all of the adult programs that are out in the different communities.

There are so many, so many deaf adults who have so many other labels attached to them now. There is truly no place to be social, no way to join together because the deaf are so separated from the other disabilities. It shouldn't be that way.

Greta Palmberg: I guess there's that magic line that's more like a chasm between K-12 and anything happening as an adult. I feel like throwing the child over the chasm and telling them, “Now you are in this world.” I wish we could bridge that better.

My son is very bright, but we struggled, struggled, struggled just to find him a high school job. And I needed help to do that, like Sally had to use family connections to do that. It would have been so nice if VR had some summer jobs for 16-year-olds or 17-year-olds to start building their resumes with employers who were used to working with the deaf so it would be a gentle start. They can't learn job skills in a place where they're teaching everybody about deaf culture. So that would be mine.

Thank you so much for coming to our panel discussion.
(*Applause*)

Sally Prouty: I want to thank you all for being here. Without you, we wouldn't do what we do.

Elissa Becker: I want to thank the students here yesterday, and listening to them. Kudos to all of you for bringing them there.
(*Applause*)