



Interviewee: **Mark Steidl & Tina Calabro**

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Interviewers: **Athena Aardweg, Judy Barricella
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Voices of Our Region
Mark Steidl
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This is a Dynavox, communication device, made here in Pittsburgh. He is accessing this with a switch here by the left side of his head, and the cursor, instead of it being something that you move with your hand, it scans around the screen in a pattern. When he wants it to stop, he clicks. When it stops he has some choices within there, and then through this, he has access to the complete alphabet, numbers. He has some shortcuts, blends and things like that to create words quickly. He has connection to the computer right there. He has all of his school works in here. He has shortened words like that. He has all his subjects here, Spanish – so it operates like a computer, like a word processor, but with a lot of other things built in for speaking.

How much memory does it have?

I have no idea how much memory it has, but it's never run out of memory. What it does run out of is battery power. After about eight hours, it's done. It has to be recharged. So the evenings are usually a fairly quiet time.

Tina, would it be very relevant to say that you might want to ...

It's not unusual for Mark to be taped, videotaped, audiotaped, picture taken or anything like that. He's quite used to it. It's very interesting, too, because it used to be, you know, a few decades ago, that also happened, but it happened more in the sense of the child being a poster child for a certain disability, muscular dystrophy, BP, raising money, good-hearted people raising money for unfortunate children, saying, "This could happen to me," and "this could happen to my children." But please give money to these children. The interesting thing about that is that those children grow up and they're not cute anymore. You know, they grow up to be adults, they get to be teenagers, they're sweaty, they get zits, not cute anymore, and that is the reality, and that image of the cute child, people still use it today.

But what the Disability Rights Movement has helped me understand, and I came to this completely through Mark, not through any experience of my own (Mark interrupts) – I'm sorry, what did you say?"

Mark: "I don't mind."

You don't mind. But I came to this through Mark. I probably had inclinations of understanding about these kinds of things before he was born, but I definitely came to understand it through him, and that is, you know, that image or that kind of place for people with disabilities in the community is not the place you want to be. It's not realistic. And fortunately for us, when Mark was born there was a very well developed disability movement that I could read about, read personal experiences, meet people and

find out what it would mean to have a view of being a person with a disability and raising a child with a disability, where that person becomes an equal member of society, a participating member of society, not a person who is pitied, separate, and so forth.

It was instantaneous. People were training me from the moment, almost from the moment, maybe not the moment, but at least the first few months of his life, that it wasn't just, you know, at least for me, a mother giving birth to a child. It's sad, you have a child that has a condition. You feel terrible for yourself and for your child.

But even with all that kind of adjustment that people go through, the Disability Rights Movement, at this moment in time is a, penetrates even to that time period in a person's life, so that they automatically are giving these ideas that just perk you up. You're like, "Oh, yeah, this could be really different." And, uh, not to gloss over the difficulties or the "aw shucks" feeling of "I wish this didn't happen to my son," but it gave me a feeling of enthusiasm about the challenge that I was facing, because I felt like I had all these people, like-minded people, people who were going to help me develop this philosophy of raising my child. And I sincerely saw for my son a different kind of future than the futures of people that I knew back in the fifties and sixties who had a totally different kind of future, a more limited future. So that was a very big change for me.

The other thing, well, I started out saying that he's used to being photographed, and so forth. He has been written about and photographed, not because I promote him and say, "Look at my kid," but because people are interested and curious about technology. How is this child, who has a very significant disability, how is he able to do all the things? Not because, "Wow, he's disabled and he can do all these things." How is the technology giving him the access to all of the other things that everybody else can do? He's a child in a regular school, regular class. He has completed the seventh grade with A's and B's. He does all of his work on the computer, through the Dynavox. He takes music lessons, he rides horses, he ice skates. He does all kinds of things and that's why people are interested in my son, and rightfully so.

And we are more than happy for people to be curious about us and to ask us how we do the things we do, because we are hopeful that we become as educators, that other people have been to us, and if we can open any doors, and so forth, we're happy to do that.

Mark –

Mark: Hi. I think everybody should get a chance.

That's right. Absolutely. Hey, Mark, can you tell us how old you are?

Thirteen.

Oh, you're one of those teenagers we were talking about? Uh huh, okay. I want to ask your mom a couple of questions and then I'm going to ask you questions, okay?

Would it be helpful if I told you what I was going to ask you, so that you could work on it?

End of Track I

Was that a two-blinker? Was that a yes or a no?

He answered "Yes."

I couldn't remember the code, but I knew it meant something.

Okay, so what I'm going to ask you about is what do you enjoy the most? That'll be my first question, so you work on it while I ask your mom something, all right?

About living. If it's school, if it's home, whatever it is. Like if I said to you, you could do whatever you wanted that would make you the happiest, you tell me what that would be. Okay?

Is it okay that I ask you questions while he's programming answers?

Go ahead.

Was Mark born here in Pittsburgh?

Yes. In Hospital.

And you knew when he was born that he had this diagnosis, or not?

Well, Mark had a situation at birth. He had a brain injury at birth, during the delivery process, and what happened was my uterus ruptured during the delivery. I had had a previous C Section, and the scar from my previous C Section came open during the delivery. He was without oxygen for about ten to fifteen minutes, and so when he was born he was quite lifeless, and had to be resuscitated, and he bounced back after a few hours. He was on a ventilator. And then he was taken off the ventilator after three hours, which they were quite pleased about. But everyone pretty much knew at birth, I can even remember being on a delivery table then. My child has a brain injury. Because you couldn't not know that, and so anyway, he was in the hospital about a month, and couldn't eat, couldn't take anything from a bottle, couldn't nurse. He did have some seizures right around the time when he was born, and those went away with medication, so he had some good strong instinct to live. He was a full-term baby, which was really in his favor. And so he was pretty normal size, average size for a baby, and pretty strong.

So he bounced back, but the injury to his brain is in the area called the basal ganglia, and that controls the coordination. All the motor coordination comes out of that. He has a little bit different kind of cerebral palsy than the typical kind. The typical kind has to do with prematurity, babies that are not fully developed and they have some leads? in their

brain. Mark's was a rush of blood to the brain, which went right to the motor cortex, and so his kind of CP is called athetoid CP. Athetosis. If you hear that, that's the type he has. It's about ten percent of all of the people that get a diagnosis of CP. Cerebral Palsy, though, the definition of that is a brain injury that happens immediately before birth, during birth, or immediately after birth. After that period of time, if you have a brain injury, it's called an acquired brain injury. Cerebral Palsy is considered something that happens at birth or around the time of birth.

So his movements are, he has a lot of movements that are unintentional movements. You know, his arms move a lot, his legs. When he's in a wheelchair, his positions and stations, so that he can control the rest of himself pretty well. When he's out of the chair he's a little bit wild, you know. Everything's kind of moving. But he really does try to work on controlling his movements through thinking about them and directing himself to the degree that he can. He works at keeping himself calm. He's also on medication for his, uh, it's called Dystonia, abnormal movements. He gets a variety of orthopedic, physical therapy, all the usual things that have to do with maintaining your body when you have neurological motor impairment.

Has he taken Baclofen?

He doesn't have Baclofen right now, but they're certainly looking at Baclofen as something – implantation of Baclofen in his spine, a pump that would pump it to his spine to give him some extra control. Control or relaxation. CP is a very multi-faceted thing.

(to Mark) Are you ready now. Go right ahead if you are. You want me to keep talking.

Okay. CP, you know, a lot of people think of cerebral palsy like just the way you move, but cerebral palsy and neurological injuries affect many, many different motor functions, not just your walking and your hand movements. It affects your throat, your ability to swallow. He has a very uncoordinated swallow, and has to use a feeding tube, because the food just does not go down the right way. You know how that feels. And if you can imagine someone trying to feed you and it's constantly going down the wrong way, it's terrible. And that's why he couldn't eat when he was a baby. It affects your stomach emptying, the muscles there, you know, the muscle that you hear a lot about acid reflux, that muscle that doesn't stay shut for a lot of people, really doesn't stay shut for Mark. He has a lot of acid reflux and a lot of erosion in his esophagus. It affects his ability to coordinate himself.

You know, going back a decade or more he had to learn to use the toilet. It took Mark four years to learn to be toilet trained, and we didn't start till he was four, because it really was going to take a lot of his direction of himself and his awareness of himself to say, "I can do this." So four years from beginning to end. Sometimes you might see older kids with CP that aren't toilet trained and I think you certainly can understand the kind of effort that would go into four years of toilet training. I know my husband, he's not here, but you might get a chance to meet him. He's hilarious. I would be the one,

you know, “We’re going to do this,” and he would be the one cleaning up multiple accidents, you know?

“Why are we doing this?”

And so the constant – but he usually does what I tell him to do.

For Tony and Athena to know, when I was in graduate school as a speech therapist, I took a whole semester class on CP. That’s all we studied for a whole semester. Quite complicated, you know, all different types and there’s a lot to learn about it. Parents have a lot to learn.

This is because of the speech area, because of the tongue. Mark’s tongue, you know, is the most used organ. The muscle that’s strongest in your body is your tongue, and Mark’s tongue doesn’t have that tone, and he doesn’t have that direction from his brain to use it, so he has to work very hard to keep his tongue in his mouth, to keep his lips shut, and he gets therapy continuously, just on keeping his lips closed. We started that and that was like, that’s going to be a multi-year process to work with Mark.

Okay, go ahead.

I like music, classical and country. These artists are great.

I missed that last phrase.

Say it again, Mark.

I like music, classical and country. These artists are great.

There’s really a difference in your musical tastes. So who turned you onto classical and who turned you onto country?

End of Track 2

There are two important people here. One of them is a babysitter named Joy, who is a classical pianist, and she taught Mark everything about music since the time he was a baby, and she takes him to concerts still and teaches him music appreciation of classical, so he’s quite well-versed in that area and he loves it.

The other important person is Dolly Parton.

(laughter)

Do you know Dolly?

He doesn't, but he hopes to meet her some day. Very interesting. Everyone has heard of Hanna Montana, the big preteen sensation, and Dolly Parton is Hanna Montana's godmother. You may not realize that. So she's on her program. So on the program she has said things, and she has her country humor and so forth.

So Mark got very interested in this woman and her unique personality. So he is now a fan of Dolly Parton. He went to see her perform a few weeks ago.

Oh, did you?

And he's seen her movies and we're going to Dollywood this summer.

Are you?

Mm-hmm.

I understand that's really fun. One of my neighbors went there and they loved it. So when she was here for the concert that you went to, she must have been staying at the William Penn Hotel, and I passed by the William Penn Hotel and saw this big bus. You know those big buses that they travel in, and it was from Tennessee, the license plate was from Tennessee, and I'm like –

He knows the bus. He's seen it on line.

Oh, you know the bus? Well, I would just say, "Let's just wait and see if Dolly comes out."

See it there, see it there, see it there.

You can see it there.

Where, at Dollywood? Well, I've never seen Dolly, but I'm a fan of country music, but I listen to more than just Dolly Parton. How about you?

Do you know who's here Saturday? Kenny Chesney.

He doesn't know him. Maybe some day. He's fixed on Dolly right now.

You know, something I've learned about my son, which is not because of his disability, but just because of who he is. He's real devoted to one performer or whatever, at a time. Sort of like, I liked the Beattles, but I couldn't get into the Rolling Stones. He's very, you know, that person right now.

Were you going to say something?

I have two CD's.

Of Dolly?

Country.

Oh, okay.

I was down at Heinz Field on Monday night, and they had the roads around Heinz Field blocked off because I finally figured out what they were bringing in in those big flatbed trucks. It was the stage for Kenny Chesney. Yes, cause they built it like a big structure and I'm thinking, "Oh, man. What an ordeal, you know? Really something.

Well, Tina, you said that you came from an Italian family and when Mark was born, how did your parents react?

Are they still living?

My mother is. Here she is right here, throwing a coin into the Trevi Fountain. Doesn't she look carefree? This was up in Verona. This was our first trip to Italy. We try to go every year.

Tell me about your parents' reaction, then I want to hear how accessible Italy is.

We haven't gone yet with Mark. I'm still working on Pittsburgh.

Okay. My family, the family I'm from is very, very wonderful with Mark. You know, completely loving and accepting. Just caring, supporting. My family doesn't get into any hand-wringing or, you know, what could have been or – you know, that's probably an Italian trait or an Italian-American, I'm not sure. Just sort of accepting people as how they are, where they are, and loving the person and not worrying or, you know, researching cures or anything along that line, just being there. In my family it was just really being there.

In my husband's family, he's not here, so I can talk about his family. They're very nice people. They're really great people. His dad has passed away now, as has my dad. He was Hungarian-American and his mother is Pennsylvania Dutch. And it's interesting that their ethnic background was a little bit different. With his dad, Hungarian-American, very loving, you know, very just love Mark, love my other son, so nothing difficult there. I think that my husband's father had a hard time understanding what we were doing, and so forth, about like what does it mean to have all this equipment and all that stuff. That's true for my mother, as well. She doesn't have the first idea about how to handle, I would never expect her to turn that Dynavox around, or, you know – if she's here visiting, she's sitting in a chair. She's eighty-five, and –

I never met grandfather.

Yeah, he never met my father. My father died the same year that my other son was born. But, no, he never met him.

We had children when we were older, in our late thirties, and my husband was a little older than me. And parents, that generation, they're not going to learn all that equipment. You're not going to leave them in charge to do a feeding tube or anything along that line. It isn't comfortable for them.

But I did want to say about my husband's mother, Pennsylvania Dutch, very German. I think she really has a very hard time understanding how happy we are, you know, and how -- she loves Mark. There's no question about that at all. But I think that just nationality-wise, there's a little bit of a difference.

End of Track 4

You know, she's a little bit more on the worrying or the perplexed side of how all this comes together, whereas I find that my mother and siblings, you know, just rolling along, and never asked a question like "What's going to happen in the future?"

You often hear people say, "What's going to happen in the future," and so forth. It's a legitimate question, but at the same time you can't be asking yourself that all the time. It's a, you know, you just can't. So I'm very fortunate to have people around me who are living in the moment.

So, what school do you go to, Mark?

I am in the seventh grade at Carmalt Academy in Pittsburgh.

Carmalt? You go all across the river to school? Wow, that's a bus ride. You go on a bus, don't you?

So, Carmalt goes to the eighth grade?

Okay. He's blinking at me, so --

And then, what's next?

Brashear. He has some options, which is wonderful. We're really city people, you know. We love living in the city where families have a lot of choices about where they go to school, and this is also true for him, in light of his disability, as well.

That isn't what we've heard, Tina. We've heard from several people that if you're not in Pioneer, if you want to go mainstream, if you will, you were directed to Brashear.

Right now, you mean? In this day, present time?

Yes.

I'm not experiencing that at all. Now I will say that what is said in one school, or through one IEP team, is not necessarily what fits better in another place, and that administrators may say one thing -- I mean, top administrators may say, "This is the way it is," but they may say one thing to a parent and it may be something different that they're saying to each other. That I can't say. I can say this, that in my experience, my vision for my child, which I bring to the school and to his IEP team and we come to an agreement about what his services will be, and where, what would be some good places for him to go to high school, and so forth, that we're all in complete sync with each other, in agreement. We have a terrific team that works on these things.

Now that being said, I have to tell you that I am a teacher. I have a master's degree in education, that I know how to advocate for Mark and I am not shy about calling administrators at the top, to explain my vision or my son's needs. So, in my situation, he does not lack anything, including choice in his education. He has the identical to what any child in the Pittsburgh Public Schools has available to them.

Now, where his disability would come into that would be, "What would be the best fit for him in terms of the kind of support that he needs." Some schools are not accessible. We have in Pittsburgh a handful of schools that still have steps and no, well they might have access to the first floor, but they don't have elevators. These older buildings, so there are some buildings that would not work.

There's some things about some support, you know, just for economy purposes. It's economics within the district. It's not economically feasible for them to put every support in every building. So that would be asking for a budget that isn't possible, so some of that steering that students have to do, with some of those resources being concentrated, but it is, the faded philosophy of the district is that the student's needs drives the process. So I, that's the only message I hear, and then I go and take advantage of that.

But there's a number of high schools that we're looking at. We're looking at Brashear because of those supports, so when you're talking about being directed there, they do have supports, so they have a good history of serving kids with physical disabilities and learning support needs. So you go in there and they've seen children like Mark before, so there's not a high learning curve for them.

Another school that we're looking at is going to be this new International Studies Academy.

Oh, where's that going to be?

Well, it's the Schenley building, you know. They're taking Schenley, at least for next year, dividing it up into a couple, actually three different locations. One of those locations would be the International Studies and International Baccalaureate. Now, one

of the things that Mark is really good at is language. He has languages in front of him all the time. He taught himself to read with the Dynavox and everything like that. So he's very good at language, and after eighth grade they have Spanish, and he's very good at Spanish. He has a special Dynavox that's just for Spanish. It's set up for a Spanish user. He switches communication devices and speaks in it with an authentic Spanish accent in his Spanish class. And so that has come very easily for him, so one of the things that we're looking at is, "Is that a possibility for him," because of the international focus, you know, that allows him to use his strength, and then also that's going to be a smaller school, because Pittsburgh is in a movement right now to have some smaller high schools, which would also be very good for a student with a disability to not have to manage a huge population of people who can't possibly know him, but a smaller group.

The other neat thing about that option is that, you know a lot of people are against this move, but looking at Mark using a wheelchair, the move to Reizenstein would be a good, would be a good move for him because it's real accessible, and many kids with physical disabilities have gone to that building. So that's another possibility.

Another possibility is Kappa, and he has taken a tour of Kappa. This would be in a Music Composition program, and so he's preparing for that, in case he wants to go that route.

And then we're looking at a Catholic school, Canevin. My niece goes there and they have a very good history of working with kids that have physical disabilities and maybe some mild learning support needs. You know, they have a St. Anthony's program, which is more cognitive, you know, similar basic type of work, maybe some functional skills, things like that. They have that program, but also at Canevin, they make accommodations for kids that are always in the mainstream at school.

So we're really looking at that, and we're kind of looking at the Science and Technology High School. It's going to be, it looks like at Frick Building in Oakland. It is accessible. It has an elevator and Mark is in a Science and Technology elementary school. There's another one. I'm not sure about that one.

I think Assumption also has an International Baccalaureate combined with Duquesne University.

Well, the interesting thing about that. He wouldn't be doing the International Baccalaureate. International Baccalaureate is very, very rigorous. That's for the elite. Neither one of my kids and no one in my family, going back generations would ever be up for an international baccalaureate.

But there are also International Studies,

End of Track 4

which is sort of a language concentration, and more kind of a global kind of orientation. I mean, really, it takes Mark about three or four times longer than other kids to do his work and everything. He, I believe, has the capacity. If he had all the time in the world, he could probably be a top student, but given how much time it takes and how much, just physically, his engagement with the world, there's things he doesn't know. There's concepts he didn't learn about the world because he never was crawling around on the floor. He never experienced them and some of those things come up. We were doing some of that the other day. We were looking at a test of some words and there were things he didn't know. Words like "ladle," you know? He didn't know what a ladle was. I showed him a ladle. "Here's a ladle. What's a ladle for?" He had to think about that. Like what is that for?

Then we talked about the Big Dipper. He had heard about the Big Dipper, but he didn't know the Big Dipper was really about a ladle. He'd never heard of a ladle. Seventh Grade, you know, and it's not his fault. So when you think about somebody progressing to a really rigorous program, there's stuff that has to be made up that may not be able to be made up for.

But Mark works to the top of his ability and my husband and I support him to the top of our ability, so wherever he's at, that's where he's at.

And then another thing is that he has a sort of laid back attitude toward life. I'm no genius. I can't do math beyond the fifth grade level. I can't tell you anything more about the stars and the big dipper, and all that stuff, so it's not a disaster that you don't have an International Baccalaureate Degree. And there's a lot of different ways to be smart, and one of the ways that I think Mark and a lot of kids with physical disabilities -- I can't speak for all disabilities, but I can speak for kids that are more or less have to sit back a bit from the hectic pace of life, is that they're very good observers of human behavior and other types of things, and understand a lot of things that are going on. Mark is very sensitive to people's emotions. He really understands what people are feeling, and that he's socially very advanced with adults, maybe not so much with his peers who are in constant motion and doing a lot of different things. I mean he has friends, and so forth, but he understands adults very well. So he has skills that have been developed because of the nature of his disability.

There's times when I _____, because you cannot appreciate how much effort goes into programming that Dynavox without seeing it.

My husband is a multi-media, he's a graphic designer. Anything you need, he can do it.

Does your husband work outside of the home, or does he ?

Tina, and I'm going to ask you this question, too, Mark, so -- but I'm going to ask your mom, too. What's been the biggest struggle for you in life? And I'm going to ask you, too, Tina.

Mine or his?

No, your biggest struggle and then I want him to tell me his biggest struggle.

He doesn't know? You don't know? Everything's a breeze for you.

Think about that for a little bit. I think I've got mine.

End of Track 5

I see everybody being independent.

That makes you sad?

I don't know if you heard me while you were talking, because he was having trouble thinking about his biggest struggle. I said, "What makes you the most unhappy?"

Well, I think for me personally, there certainly isn't any one particular thing that's been the biggest struggle, because every step of the way there are struggles associated with every stage, every stage of Mark's life, and every transition that a public change, that is, you have to go along with, because you're in a, you know, not just one change, but many. There's a kindergarten, the new school. That's always a challenge for everybody, but for Mark it was a huge transition with thirteen people sitting around the table discussing what was going to be the next step.

I think that just in terms of emotions, the things that have hit me the hardest besides when Mark was first born, which completely was devastating probably for a couple of years, to my every thought. And I really believe that it's underestimating it to call it stress. It's more like something that goes to every cell of your body and you're like traumatized, even though I was saying, intellectually you know what you're going through. I was able to make plans, and so forth, but in terms of my feelings of grief for him, for my husband and myself, for our older son, I think especially for my older son initially, because he was our one and only for six years, that just was like a physical trauma to me that I am certain probably affected my health, even though nothing actually was happening that was visible to anybody. I just felt that I was in a trauma for a couple of years, emotionally and physically.

What I'm finding now is, I found that when Mark turned ten, I found that that was a very hard moment for me because I had worked with him and with all these other people for a decade, and looking ahead to doing that for another decade was overwhelming. It was just at that moment in time, I felt like, "Am I really going to be able to do this, to maintain all this energy and do all these things for another decade?" So that hit me pretty hard for a short period.

And then, you know a lot of these things, life has its way of smoothing them all out, not just because of time, but also because of what's built into us as human beings, that just at the moment when I was thinking, "I'm not going to be able to do all these things for Mark," he started to show me that I didn't need to do all those things for him. Because he was growing up. So the things that I had been doing for him the past ten years were not the things I was going to be doing for him the next ten years, and the understanding of that made me realize that I could do it then. It made me realize that I could do it make it more interesting, and also that he was going to be participating in that for me. It wasn't just going to be me doing all the work. So that was a really difficult moment right in there.

I think that another thing that a lot of families notice is your marriage. We have to work really hard at our marriage.

How long have you been married?

Twenty years. We'll be married twenty years this year, and it is extremely difficult. Why is it difficult? Because your life is driven by the realities of, you're not going to be hurt by this, I hope, of disabilities. It's not you. It's the features of things that we do every day. It has nothing to do with how we feel about you, Mark, or anything. It's the work involved that is incorporated into each and every day. And it adds to everything else that we have to do or want to do. And after a certain number of years of just jam-packed, we literally go from about six or seven in the morning till eleven o'clock at night. Many days we don't sit, except to sit at our desk to do work. There is no, see this is why we have this as our sitting room. That's the living room. But when we moved into this house, we said, "We don't sit anyway, so we can make that the diningroom. You know, we don't need chairs, because we never sit. So that is the aspect of our lives that is very difficult, because when you're really tired like that all the time, we're super tired all the time. We don't have time for each other. We're like sick of each other. So we have to work really hard to keep our relationship fine and stay pleasant with each other, not get too bossy about things that need to be done.

And every once in awhile take a trip to Italy.

He doesn't go. No, he doesn't like traveling, cause he has this tree, bonsai trees, and those are his, like children to him. He can't leave them, and then he just doesn't like to travel.

So you have a date every week or something?

We do go out together. We go out every Friday night.

We have a lot of people helping us, too. At any given time we have about four sitters. Whoever's available, they come in –

You've trained them?

Yeah. I like to get these young people from graduate school usually. They need to make some money. They're usually Physical Therapy students or Education students, so they have the right sensibility and they're happy to be making money. They like being around a family. Most of the time they're women, who have become daughters to me, which is really nice, because I don't have any daughters, and I get to live through all their engagements and everything. So we get to do all, we organize our lives so that we can have some fun.

(sitter: "I've only been in grad school a year. When I came here I didn't know anyone but the families I babysat for became my families.")

You know, it's very interesting how that works. Which makes me think about some of the things that Mark's disability or condition has brought to us. You know, we've never had a sitter for a thirteen-year-old child, so we have, I mean, not that the sitter has to do that much. They just have to be around for safety reasons, and so forth, but he's brought all these people into our lives and all these relationships, and, uh --

And I'm sure you don't mind having these young college students here, do you Mark? Girls?

Our neighbors all laugh, because it seems like every sitter we have, their name begins with K. Kristin, Katie, Katherine, Kelly. And they can't keep them straight.

Well, I'm going to ask you another question and I hope it will be a little easier. I'm going to ask your mom and you the same question. What are you the most proud of?

End of Track 6

And Tina, the same for you. What are you most proud of?

Do you want to write something and I'll talk while you're writing. Okay, you think and I'll -- You know, I want to answer that question by telling you what I heard somebody else say they were proud of, because when I heard that, I was like, "I wish I had said that," because it was a really good way to feel. What it was is that some friends of ours that also have a child, a daughter with a disability, about the same age as Mark. They live in the South and we spend a lot of time with them. They're farmers and they have a lot of cattle, and they have that kind of a country life, and they're very involved in the disability movement and do all this kind of stuff. And at one point the father of this family said, "I'm very proud of all my children." They have three other older children without disabilities, and they have the one with disabilities, the youngest child with the disability, and when he said that, "I just felt that that's the greatest way to say it, that you are proud of all your children. Without even talking about it any further. You're proud of all your children.

I'm making it.

You're still working on it. You're making it. Is that your answer, you're proud of the fact that you're making it. Is that your answer? Okay.

I'm making it.

Yes, you are.

I'm amazed, when I was coming in the back door, you have like this whole stable of wheelchairs. Like, "Ooh, aren't you lucky!" Like this one stopped this morning. I was waiting for the elevator and like this, it stopped dead on me. So I don't even have a backup.

Yeah, we also have a lot of wheelchair parts in the basement. When he outgrows them, my husband takes them apart and rebuilds them.

I wish I had the ability to do that.

Do you have any questions about funding, how we pay for all kinds of things, and ?

Well, I was going to ask if there was anything you wanted to say, that I didn't ask.

Well, I think it's really important to say, because when you have a child with significant disabilities, and he needs, basically around the clock supervision. Mark can never sleep without somebody within earshot, because if he got stuck somewhere or whatever. So you really have to watch twenty-four hours, even though he's not sick, but -- so then you're talking about like nursing or sitting, like paying for the kinds of sitters we're talking about and all that kind of stuff. You know you really have to work the system to make sure you're getting your piece of that pie.

So the same thing that goes into all this educational advocacy, which is like they're paying the bill, you're advocating there and telling them, working with them to agree what you want for your child, and they're going to pick up that bill. It's not going to cost you anything. But outside of that system, you really have to advocate, and all of the families do, to make sure that all the various funding streams, that they understand them, that they fail to write things that they've got to say, and it's just -- we have a really good system. I'm not being critical. We have a funding stream. Some places don't have that. But you really do have to, you have to work it, and some people work it better than others. So we, you know, I work those systems pretty hard to make sure that he is getting what he needs. And I'm not talking about frivolous things. I'm talking about the respite, the, like even the Friday night out with my husband, I have to have a trained person here, somebody who knows how to operate a feeding tube. You know, that's important. It's not just a one-on-one care medically, but it's like your family life and everything. And the government, the system, they understand that, that a healthy family is going to produce a healthy child being raised.

That being said, we're also in a better situation than some families because Mark does have a trust fund, a Special Needs trust that he can use, and that gives us some of the additional things that we need that we would never have. We wouldn't be living in this house probably, which is not a mansion, but we wouldn't probably have moved here and been able to renovate the house without going into a lot of debt, if it wasn't for Mark's Special Needs Trust.

Did you do that through Achieva?

No, we have a Special Needs trust through Mellon, and that was a result of a settlement, so you know, that's funding that is there for Mark's needs, for his whole lifetime. And then, my husband and I are in charge of deciding what he needs. So one of those things that we decided was that we needed to move. We needed to move from a house that was three stories and not accessible, to a single story home. We put in an accessible bath in the basement. We put in the lift back there, the ramp, different things. This house is totally equipped for Mark to live in, as a child and as an adult. Never would we be able to afford to do that. And I know many families that have set up their house like this with their own money, because they're on a waiting list, for labor funding, and there is no home modification funds for families like this, so it is a real problem. They've gone into debt. And I've seen a lot of people, they have not gone into debt to do it. They've lived with their situation, carrying their child, dragging their wheelchair up steps, carrying their child upstairs into the bathtub. We don't have to do that. We put him into a shower chair and he rolls into it.

And, you know, my back hurts just with the small amount of things I have to do. Imagine if I had to carry Mark up and down stairs, so anyway, I just wanted to say that.

But you really see a lot of families that have things that causes that child not to be able to live at home anymore. That's so sad.

Exactly. Like we've told Mark many times, "When you're an adult, and you want to live here, you can stay here and your dad and I will move. We'll live with you if you want us here, but basically, yeah, that carries right through to adulthood.

For a lot of people, the Office of Vocational Rehabilitation, when you reach sixteen you can become a client of the Office of Vocational Rehabilitation, and they will pay for an awful lot of things, but for children,

I could take Mark out of his chair and I could show you that he's as tall as

End of Track & end of CD

Mark and Tina II

I am. When we stand together, imagine lifting somebody your own size and weight. And I know that you have met men and women in their older years who have been lifting their adult children.

Yes, absolutely.

And there is no need for it. If only a fix, if only a lifting system, an elevator, a ramp. But you're right, that's basic as the kids get bigger,

We were just talking about the Variety Children's Fund. And I think they provide a lot of equipment for children, but it's only a piece of what you need.

I try to work with a lot of families and try to mentor them, to try to give them information that they need. You know, if you have the time to -- it's nice when they have something like Variety there, and that's great, but then when you go to a family and say, "Well, apply for that. Fill out this application. There's money over there." Some of the people I talk to they don't have time to do that. I can do that. I have a husband who's living here with me to share the work. I'm an educated person who makes a higher hourly rate than others. So that's not to say, I mean, our system, our lifestyle here in Pittsburgh is a high quality, but there's some little tweaks to it that it's like you can't understand why those things can't be tweaked.

Excuse me for ranting, but it's like when you go in a school, Pittsburgh Public Schools, these buildings aren't air conditioned. You know, and you're like, "How can a school not be air conditioned in this day and age?" These kids are in there sweating. So you're like, "How can you do other things and not do that?" So, anyway, excuse me.

One question I thought of while you were ranting. You weren't ranting. About that funding and equipment. Now it left me and it was important. Did you have something you wanted to say, Mark. Talk amongst yourselves.

What you said, it was a while back that you said it, in terms of the ladle and the Big Dipper. I mean, that's one of the big problems with standardized testing. I mean in terms of a measure of intelligence. I mean, yeah, what does that mean, if you're not exposed to it?

That he didn't know what a ladle was, really.

So if it's on the test, then you miss it. It keeps you from getting a better score. It's like that whole "So what is a measure of intelligence?"

Definitely. They talk about testing. They've tried to make it culturally sensitive. Because there are some people, like one he had to take a test in the kindergarten. There was a picture of an iron and he didn't know what it was. I'm like, "Well, he ain't never saw one of those around here." So they try to make these things culturally sensitive, so that they can accurately see what some kids that are economically disadvantaged might

have missed out on or they just don't have access to it. But I think there's also when you're talking about kids with disabilities that, depending on their disabilities, they develop some strengths, and they miss out on some things. It's almost impossible for them to get an IQ score on a kid. And so there is this concept, and I know you guys know it really well, the least dangerous assumption. You know, this is a very big popular concept right now which is you look at somebody and instead of making a judgment about their level functioning, based on the way they look or their ability to communicate, that you make the least dangerous assumption. Which is you give them the benefit of the doubt, you know. I don't know how smart they are or how much they can do. I'm going to put all the things out there and make it possible for them to do the things that everybody else does, and see what happens. If they can't do it fine, but I'm not going to make that judgment before I hand those things out to them. And that really impacts kids with significant disabilities in elementary schools.

Tina, I thought of what I was going to ask you. When you said that you work a lot with parents and they don't have time to fill papers out and do whatever. Is there no organization out there that will sit with a parent and, like if they have to fill out an application for an Access grant or housing or something, that will do that for them? Is there no organization out there?

Oh, I'm sure there are. I don't know about all the supports that are available for families, so I really don't know. I think we talked about it yesterday at that meeting, where the one woman... Your Department of Human Services was there, talking about how she sits down and teaches people and she would like to have a thing, a book to teach from, and so I know that there are those things.

Well, I was thinking about the program that we have in our office, the Allegheny Link to Aging and Disability Resources, where people call us and we want to be the last call they make. We don't say, "Here's a number. Call this place." We try not to say that. So if you need to get in touch with the Housing Authority or you need some type of housing, or you need equipment, we'll do the research. We'll call you back and tell you what's out there, and then if there's an application that you have to fill out, we'll fill it out with you. If you want. It's up to the person what they want, but if it would be easier for you to have us talk you through it on the phone, we'll fill it out and we'll send it to you for signing, or whatever. We do that, and I think that that's the kind of thing -- when you're talking, I'm thinking, "Parents probably need this," because we explain all this to them as we're doing it.

There's a lot of parts of the safety net all over the place. There's social workers in schools, developmental advisors, you know, all of the approved private schools for kids with disabilities. Social workers and that type of... so I think there's a lot of people that don't lack the support. I think it's just, it reflects how complicated our system is, that we have to have people. The complication is good and bad, because we have all these systems and all these things you can get to help make your life better and easier. But you have to work hard to understand it and to participate in it. You almost need somebody to

teach you or help you do it, but I think that it's not that people are without the help. It's just hard.

And I think the other thing that I sometimes think about is, you know, the kids that -- you know the term "high flyers." You've heard that before, that kids with disabilities grow to be adults with disabilities. They're the high flyers, they're the ones that, they're the role models, you know.

Or as we like to say, "the super crip". I don't want to put that on the tape but...

Well, it is there now, sorry. It's gonna be archived forever.

Right. It gets into that, you know, that's a negative, but if you look at someone like Harriet McBride Johnson, you know, she's a high flyer --

She died.

She died? When?

Just in the last two weeks.

Oh my god. I was just reading something she wrote yesterday. Terrible.

But we're talking about a kind of person that they become a spokesperson for the disability movement. They're you know working toward their own personal goals. They succeed. They're not necessarily putting themselves out there as a model, but they're achieving to their potential. You know, really, they call them high flyers. And there's been some research that shows that the person in the individual's life that has the most impact on that outcome is the mother. The mother's education and the intention, energy or focus, being focused on that goal. And so I recognize that my child benefits from that and that I know that a lot of, there's people helping and they're trying to do a lot of things that help people get positioned to do things well for their children. You know, "Apply for this, apply for that."

End of Track 1

But one of things that I tell families, because I talk to them a lot, and it's not to like say, "Look how good that I'm doing," but it's to say, "You've got to work harder." You know, like "I'm sorry, but yes, it's difficult, but there is no other way. If you want that outcome, you've got to understand that nobody is going to hand that to you. That you've got to study it. You know, you've got to work harder. You've got to spend two or three hours a night with your child on their homework. You've got to program the Dynavox."

You know, just all of those things. So anyone that comes to me and they're like "My school district, blah, blah, blah, they're terrible." I mean I don't doubt that they do have a problem. But how do you correct that problem? It all goes back to the individual. You have to do it, and, so anyway that's --

Some parents are so overwhelmed, they can't move. They can't fight. They can't do anything, and that -- I try to help parents through that. But some parents have ten kids. Some parents have, you know, a whole bunch of other kids that they're having to fight with or for, or whatever. It's really, really, really hard.

Well, I understand that and I'm not saying that, you know, they have, people have hard situations, no question about it. It's just true. It's just that we, parents that are raising kids with disabilities, like any other person, has to have very strong work ethic. You've just got to go back to whatever you have to do.

I think that's it, Tina. I think you're right. The work ethic. I see a lot of people with kids coming up these days. That work ethic, it's just not the same as it used to be. With all types of people, disabled or not, it doesn't matter. And I don't know why....

We're turning into those people who always talk about "this younger generation". I'm turning into this cantankerous old man.

I can remember years ago, I went to this company. Through my dad at his work, I could get his medicine. So I went there and I was waiting for his medicine in the lobby, and these kids were coming in, one by one, looking for a job. Or no, they were there for the interview, and I couldn't believe my eyes. One girl came in with like a ballet skirt on. And this boy came in in a tee shirt and jeans and, I'm like, finally I said to the receptionist, "They come looking for a job interview?"

She said, "Oh, yeah, you wouldn't believe how they dress when they come."

So somewhere along the line kids aren't being taught that kind of work ethic and what it means to work hard, and that.

A friend of mine who also has a child that has CP. She told me that she tells her son, who was the at the time four or five years old, that he was going to have to work harder than other kids because of his disability. That was just the way it was. And so get used to it. And that was a good piece of advice for me and that is the philosophy I use with Mark, that "Yes, you have more work than other people to do." So do I, but it's just the way it is and just keep carrying on, because that is the only way.

Tina, who has been the biggest influence on you?

I think Liz Healy. I think there are many many people, but I think I have to put Liz above anyone because of her passionate belief that in the right of every individual to be included in any and all aspects of society. That there is absolutely no justification for excluding anyone from participation in society.

(some conversation that could not be heard clearly)

So I asked him what he's going to do this summer.

Going to Dollywood.

That's the highlight. Okee-dokey, Dollywood, Dollywood.

End of Track 2

I am music composition student of Jeremy Smith at Hope Academy. I have been interested in music since I was very young, because I had an adult friend named Joyce that would play piano for me. Joyce introduced me to classical music, ragtime and the greatest musical artists of all time. My favorite composers are Beethoven, Bach and Mozart. I have attended many concerts by the Pittsburgh Symphony and I attend music camp each year which is taught by Lucas Richman, (???) conductor of the (???) Symphony, Andrew Clark director of Tufts University choir, and Brazilian singer (???). My Hope Academy teacher Jeremy Smith has taught me to make music composition with (???) structure and enjoyable melody. So please enjoy these two short compositions that I wrote this year. Thank you.

(Music plays.)

I think you need to pick a note for that rest. You want to try a different note? (Music plays.) A high note? No? A low note? Let's go back, right? Like from the beginning. Let me know where you want me to stop. Don't just enjoy, listen. Okay. Just look at the flute line, talk about some good things here. If we look at the flute line, I like that you have... see how you have the dotted rhythm here and then the dotted rhythm two bars later? That causes good form, doesn't it?

(Music plays.)

Okay. Okay. Beautiful, beautiful.