



Interviewee: **Aubrey Lowry**

Interviewee Number: **46**

Interviewers: **Athena Aardweg, Judy Barricella**  
**& Tony Buba**

Date of Interview: **June 11, 2008**

## Aubrey Lowry

**My first question is, that is picture is on your leg. What is it?**

(woman's voice)

Aubrey's mother: Yes. When I was in art school, when Aubrey was a baby, it was about the mid-seventies, I drew it and it's actually a copy of a 13<sup>th</sup> Century unknown artist, who did Mary, the mother of God, and it was hanging in Carnegie Museum, the Sarah Scaife Library, and I loved it so much, they wouldn't let me take a picture of it, so after the class - no, it was against copyright laws and everything- I went back and they would let me sketch it, so I sketched it, and then I loved it so much I had it tattooed on.

But actually, the story of the tattoo was my daughter was getting to be thirty, the big 3-0, and I was getting to be fifty, 5-0. We wanted to do something that would mark our birthdays, that we did something mother and daughter. I she- I said, "Well, you pick it," and she picked it!

So I was brave and I got one.

**Good for you. Good for you.**

**Okay, well Aubrey, if you could tell us a little bit about yourself, where you grew up, if it was here in Pittsburgh or not, and if it wasn't, when you came to Pittsburgh and what you're doing now.**

(man's voice)

Aubrey: Well, a little bit about myself. Okay, that's a great start. I was born in Davenport, Iowa, West of the Mississippi River and then I was- I moved to Pittsburgh when I was a very young boy, after my parents divorced. I lived with my mom and my sister and we grew up in Shadyside. Right now I'm in Oakland, and what I'm doing right now is goin- I plan on going to New York City to go to a center called Helen Keller Center for the Deaf and Blind.

**So you're going there or you're working towards it?**

I will be going there as a student.

**Oh, when's that?**

This August, I think.

Because I have Usher's Syndrome-

**Oh, you have Usher's Syndrome, okay.**

It's a genetic disorder that I was born with, I inherited it from the family line, and I have tunnel vision, night blindness, color blindness, name it, you know, macular degeneration, retina pigmentosa, it's hard to describe, but I'm legally blind and I'm hard of hearing. I wear two behind-the-ear hearing aids.

**So how much do the hearing aids help – if um, I mean you can hear me pretty well with the hearing aids?**

Definitely, I can communicate with you just fine as we are right now.

**And your sight – has it been, um, so you can see me?**

Yeah. I have central vision. I have a loss of peripheral vision.

**How has that progressed, in terms of you losing your sight? Is it- when did you start losing your sight?**

When did I start losing my sight? When I- in my teenage years. I gave up my driver's license when I was about twenty-one. I obtained it the day after I turned seventeen. I wanted to get it when I was sixteen.

**Yeah. What um, can I ask you how old you are now?**

Yes. I'm thirty-five. I just turned thirty-five on May 20 of this year. I was born in 1973.

**Because you knew you had Usher's Syndrome, you knew you were going to be losing your sight.**

Correct.

**So how did you prepare for that?**

I went to Bible School, actually. College, Geneva College, and I was living off campus, not in a dormitory setting, but off campus, as I said, with my minister, who I met through my mom. He had a small, very small non-denominational church. It was- it was very nice and it was family life, and I lived in the basement of their house. We built a room out of pallets and put a floor down and put up walls and I lived there in the dormitory- lived there in a room and I commuted back and forth for as long as I could to Geneva College as a student.

**While this was going on, were you learning- have you had a need to learn Braille?**

Yes, I recently completed an eight-week program at BVRSP and all the instructors there were very nice and my state counselor is from BBS. Her name is Kathy Hillbeck. She advised me to take up some training to learn Braille. Uh, I learned Braille- I completed successfully the language of Braille One. That is A through Z on 2/10.

**Okay, okay. Was it easy for you to learn or was it hard?**

It was very hard at first, but practice makes perfect.

**Yeah, yeah, right. Right. And your hearing loss, were you born with that hearing loss?**

Yes, I was born with my hearing loss, and I- it took three different hospitals to diagnose me- to finally diagnosed me correctly, that I have a hearing loss.

**Was that in Iowa or was it here in Pittsburgh?**

Pittsburgh, but Children's Hospital of Pittsburgh was the one that found that I was hard of hearing when I turned three years old.

**Wow. Were you talking?**

I was talking, but I had to- I went to DePaul, I don't know if they're still there or not-

**Yes, because we were there yesterday.**

Brookline?

**Well, they moved, they're over in Shadyside now.**

Okay, yeah. When I was in Shadyside I commuted back and forth, with my mom's assistance, to go to DePaul, and they did not believe in sign language, the use of sign language, but I was kind of fortunate, in my situation, they were right. Speech therapy would help me. I speak as a deaf person does, but with Speech Therapy I can speak clearly enough that people can at least understand me one way in our communication. One way or another I get my message across.

**Oh, you're perfectly understandable.**

But with the correction of hearing aids, I can hear what other people are saying. Not always, but sometimes.

**Yeah, yeah. So did you go there through twelve grades?**

I'm sorry, please repeat.

**Did you go to DePaul through the whole twelve grades?**

No, went to- I transferred from DePaul to Liberty Elementary School. I was in a Special Ed Program, but partly mainstream for some of the courses, like spelling, or things like simple classes like that, mathematics.

Aubrey's mother:  
May I interject?

**Yeah, absolutely.**

The school board, the Board of Education, was offering a pilot program of mainstreaming at that time. Aubrey was maybe five years old, it was like 1978 and on, and so Aubrey was one of the guinea pigs, if you will, for the City, who is now fully mainstreamed. So back then, they were just piloting some schools for the programs to see if that's the direction they wanted to go. So I was very happy to have Aubrey participate in the mainstream and go to school with his sister in his own neighborhood.

(Aubrey interjects)

Wow, I didn't know that Mom, sorry!

(Aubrey's mother to Aubrey)

Well no, I mentioned the Board of Education.

Aubrey:

Oh, that's great.

Aubrey's mother:

-but I mean you were one of the candidates, so I was very happy you were suggested, because you have to follow the money trail, too.

Aubrey;

Okay.

**So, he was five, but he went to DePaul. How did that work?**

Aubrey's mother:

He went to DePaul from the age of 3-1/2 to 4, where I transported him, but at 4 the Board of Education would provide transportation and from 4 to 5 he went to DePaul. And so then they suggested that he be a mainstream candidate because he went from maybe 50 words with half phonetical syllables, to a vocabulary of 4,000 in that year-and-a-half he was at DePaul. So since he was intellectually sound enough [Track 2] to handle the stress that early, we decided to go for it, and he's been an Honors student in everything for the thirty-five years I've known him.

Aubrey: Thanks, Mom.

**Okay, so he actually went to public school then, from, was it first grade then? Or was it kindergarten?**

Aubrey's mother:

First Grade. It was called Liberty Elementary School in Shadyside.

**It's still there!**

Aubrey:

Yeah, I went through all five years there, all five grade levels in Liberty Elementary School.

**And then where did you go?**

Then I went to Reizenstein Middle School.

**What was that like?**

It was kind of, uh, interesting. Again, it was set up like Liberty Elementary School.

(Phone rings and is answered briefly.)

Aubrey:

Please excuse us.

Aubrey's mother:

I was very impressed with Aubrey's art skill. It was one of his mainstream classes. So his hard academics were in the resource room with a, um, trained professional, and he was elected out of five hundred students in the whole facility, by his principal, to be one of two students to go to Carnegie Museum's art classes on Saturday, and Aubrey participated for two years. He went every Saturday, and in fact, one of his pieces that he accomplished in chalk was hung and displayed as a final year's presentation up in the museum. So he actually had his art work (and I have pictures of all that) hanging in the museum. So he was very, very happy to participate in that.

**Very nice, very nice.**

Aubrey:

Thank you, Mom.

**Well, I do want to go back to Liberty. Do you want to talk about that again?**

Sure.

**Because if you were in Special Ed at Liberty, or whatever they were calling it at that time, were you in Academic classes, or were you in Lifeskills?**

Academic classes.

**So, but you were in a self-contained classroom?**

Mm, hmm.

**Okay, so you were in with a variety of disability types?**

Actually, no. It was- one student was multi-handicapped, but one thing that we all had in common, there were about eight of us, is our deaf- was our deafness. That was back in my days of youth before my sight began to deteriorate.

**What about at Reizenstein? Were you in all regular classes there?**

I played a lot of hooky at that time. I shouldn't, but I –

Mother:

It was mixed. Half was Resource and half was mainstream. So his English class was resource. His math class was regular. He had two homerooms, a regular classroom and a resource room. So it was difficult for him because of the larger classrooms, and he was, at eighth grade, getting a little frisky and his A's went to C's. And to interject something there on his behalf, it was kind of like the resource room didn't want him, and the mainstream class, the regular class, didn't want him, and they both kind of let him slip through the cracks. And that's why he was getting frustrated.

Aubrey:

Yeah, that was part of the reason.

Aubrey's mother:

So it wasn't that he was being bad, but – so, the Board of Education and I, at that time, disagreed also. I almost went through due process. They wanted to send him to Brashear along with the class roommates. You know, they all went to Brashear, which was fine, but I had an opportunity to send him to Gallaudet University's model secondary high school in D.C., and I said I would like to approach them just for transportation needs back and forth. Well, they denied me because they wanted him at Brashear.

I said, "Fine, we'll do it without you," and we did. And we went to Gallaudet. We had three-day orientation intake, and he was accepted, and he made all A's when he was there.

**Fabulous.**

Aubrey:

That's where I learned sign language. I didn't know what my homework assignment was. I had to go up to the teacher after every class and have them write down my homework assignment. I learned myself- I forced myself to learn sign language through the deaf culture at that time.

During that time Gallaudet University was recognized worldwide because of their presidential needs for the campus. To clarify myself, they wanted a deaf president for Gallaudet University, so they demonstrated, like- quite a parade-they lobbied for it, their rights

**That was in the nineties?**

Aubrey's mother:

That was '88. So, he had an eventful year his first year on campus. 'Cause normally the high school students were not intermingled with the older university students. But that was a hot topic to have a non-hearing person and an alumni peer to be in offices. So that was exciting for him.

Aubrey:

I didn't have to learn tactile sign language, cover sign, like Helen Keller uses at that time because I still had a lot of sight. I was still pretty young. My sight deteriorated after I went to- my sight, my Usher's Syndrome, which is RP with a hearing loss, so to say, was diagnosed by WPSD actually. See, the first two years of high school I went to MSSD Model Secondary School for the deaf in D.C., on the campus of Gallaudet University.

Hold on, can we back up? Can we back up and explain all those acronyms? The WPSD, can you explain what that is? They're definitely- I've heard them but I don't remember.

Aubrey:

Yes, okay, I went to WPSD, and...

Mother:

And that means Western Pennsylvania School for the Deaf in Wilkesburg.

Aubrey: Western Pennsylvania School for the Deaf- I'm sorry. Actually, it's on the borderline between Wilkesburg and Swissvale, and Edgewood. It's crazy, kind of- it's right in the point, right in the center of all those towns.

**And then you went to the model, you said MSS model...**

Aubrey: Model Secondary School for the Deaf.

**That's what I really didn't know, but I couldn't remember all those letters at once.**

Aubrey: Okay, okay, I'll try to simplify this stuff.

Aubrey's mother:

Well, he enjoyed Gallaudet. he was still a little homesick. He was still very young. He was only fifteen, sixteen, seventeen, so he came home to be with family, and actually when we say family now, we're going to do a family that adopted him practically. They didn't legally, but Pastor Ed Charney and his wife and their children had a home near Geneva College, so Aubrey would go from Pittsburgh (and his mother and sister) to Geneva and live with this family.

**For the rest of high school?**

Aubrey's mother:

Well, back and forth. When he needed to be- during Monday through Friday, you know, kind of high school, I need to be here- he was here. On the weekends, holidays, summer vacation- the whole half of the year that he wasn't here, he was there. So we shared him.

Aubrey:  
When she says there, she mean Butler, PA. Evans City.

Aubrey's mother:"  
And he had so much fun there. They're very loving.

**So where did you go to high school here?**

Aubrey:  
Where did I go to high school? I went to, the first two years at MSSD, the latter two years here in Pittsburgh, at Western Pennsylvania School for the Deaf.

**Oh, okay, so you went to high school here?**

Mother: He graduated from here.

Aubrey: I graduated in a class of thirteen.

**That's nice, you know?**

Aubrey:  
I know, it was a charter school. It is a charter school, still is.

Mother:  
I have something to interject on a mommy note. Actually, when he wanted to return from D.C. to Pittsburgh to finish high school, the Board of Education was questioning me, "Well, now, all of a sudden you want Pittsburgh Public Education?"

I said, "No I don't. I want him in the deaf school."

They said, "But [Track 3] he should be mainstreamed."

I said, "For sixteen hours of the day and the weekend, he's with a normal-speaking home, he's in a normal community, has normal friends. His academics need deaf attention, and then deaf-blind attention, as his prognosis would carry through, and shortly- we didn't know if he would be fifty years old, forty years old, thirty years old- when.

But I won this time. They let me have my way, my wishes. I didn't have to go through due process or anything. They provided transportation, they allowed him to go to the deaf school, being that he had all the community and family support in the hearing world, is what their conditions were. But I had to fight for him to leave and fight for him to get back.

**If I could just explain a little bit of that for the tape -- part of the reason is that the districts has to pay for Western Pennsylvania School for the Deaf. The districts are not willing to pay for specialized school if they feel they can provide something in their, in your home school, but you as a parent, really have the final word on that.**

**The law gives you the final word. But you're right. You have to sometimes fight with the school district and --**

Aubrey's mother:

Not to name names, but right now, Dr. Penn is in Harrisburg doing wonderfully for the State of Pennsylvania, but Dr. Penn was in Pittsburgh, a local guy back then, and also a Kay Couples. Kay Couples was a mister then, but has soon, then been Dr. Couples, so I was, you know, that man, also at lunch I guess, we used to have all kind of meetings and the poor guy really tried to assimilate Aubrey into keeping him here in Pittsburgh, and I just knew Aubrey had excellent skills and I wanted the best for him, not that Pittsburgh isn't good, because a lot of his peers went to Brashear and then they went to Pitt and they have Masters levels. So for them Brashear worked out. But I just felt that Aubrey had other options and that D.C. was not be something that would be less than what Pittsburgh would have to offer. It would be the same or more. Just like Helen Keller in New York. Helen Keller is great for academic and training, but he's coming back home, so it's been a whole year we've been working on that process.

**We'll see about that!**

Aubrey's mother:

I know, I know, I'll get a call from New York, "Hey Mom, they love me, they're giving me a job and I'm staying", but anyway, I'm sorry to get off track, but I like those little Board of Education notes. You know, cause everything was so new and developing back then, and they were -- everybody was running to due process. I never had to get to that point, but you really had to push it to almost that point.

**What's interesting for me about that is that, excuse me, for parents who wanted the inclusion in the public schools, Kay Couples is really a proponent of inclusion. So he was really, he's been so helpful to so many parents, who were fighting for inclusion in Pittsburgh public schools. He's still with the school but he's no longer in that position anymore.**

Aubrey's mother:

Okay, excellent. I hope they're both doing well. I didn't mean to, you know, be the little grain of sand in the pearl or, you know, the oyster that made the pearl that irritated them.

**No, no, but I think that's an interesting thing because you're right. If your child can get a better education in a "segregated school," so be it, because these are the building blocks for his life. Absolutely.**

Aubrey's mother:

Right. Well, actually Gallaudet was very, very strict. We had to do our family history from my parents to me to him, plus we had to do a series of tests, all kinds of tests, plus his academics, plus we had to be down there and be interviewed for three days, and then we had to wait for two weeks before we heard if the thousands of people with only maybe fifty openings, if Aubrey could be one of those people. So Aubrey was prepared to have to stay in Pittsburgh, but the Lord opened the door and answered our prayers, and

he excelled. He was straight A's. He even learned to play a guitar. I never thought he would do music.

Aubrey:

Yeah, we performed a rock concert. We pulled together a band and I made it. I'm not real crazy about it. Like it wasn't a five star rating or anything, or on the cover of the Rolling Stone, but it was fun and I learned some chords.

**So, when you graduated from high school, what did you do after that? You went to Geneva?**

Aubrey:

I went straight from Geneva College. I mean, after high school. Upon completion of my high school graduation, which took place at WPSD in 1992, I went to Geneva College and was immediately accepted.

**What did you study there?**

In the Fall of 1992 I majored- I picked a major because they required us to pick a major, and I didn't know what I wanted, so I picked Biblical Studies, and a focus in Philosophy.

**Did you graduate with that?**

Yes, I did. I graduated with a B.A., 3.48. **Wow. So did that qualify you to be a teacher of the Bible, or –**

In my affiliation with the minister with whom I lived with and known for so many years, I could be equally licensed to be a minister in a non-denominational church.

**But you didn't want to do that?**

Aubrey:

I'm sorry?

**You didn't want to do that then?**

Aubrey:

I didn't feel that that was my calling because my duties at that time was at the level of the deacon. I was a deacon for so many years and –

Aubrey mother:

Actually, I'd like to put in that Aubrey's interest is law, and he'd like his Master's level in some type of situation with the judicial system, and the last ten years his health prevented him from obtaining a Master's, but now he is so much better and we're thinking Helen Keller can help him do that at his own pace, and he can tell you about the Law part.

Aubrey:

Well, I was just interested in pursuing a J.D., Juris Doctor degree. I looked at all kinds of law schools, schools in California, schools in Pittsburgh, the State of California and the State of Pennsylvania mostly. I say California because there's a lot of good law schools there. Not that there aren't any good law schools on the East side of the coast. I've checked out Concord Law School on line, but they're not accredited by the ABA, American Bar Association, and unfortunately, I turned away from that opportunity, so Lord willing, if I- after going to Helen Keller in New York, I'd learn tactile sign language like I did Braille I, I will equip myself physically, mentally and in every other facet of life, in every way that I can prepare myself for the future of higher education, higher than a B.A.

**Tell us a little about Helen Keller Institute. Is it called "Institute?"**

It's not. It used to be. It's called Center for the Deaf and Blind.

**What will you do there? You'll learn tactile sign, is that right?**

Right. I'll learn communication skills, daily living skills, things like how to tell what color your clothes are, by labeling technique. For instance, you can have -- there are [- Track 4-] several different methods of doing that. That's a class in and of itself.

Aubrey's mother:  
Mobility

Aubrey:  
Mobility, cane- with walking stick or cane for the blind. I used to have a guide dog, but he was disobedient, so I had to send him back. His name was Calvin and I miss him.

Aubrey's mother:  
Yes. We had him for ten months. He was donated, a \$30,000 donation for Calvin and Aubrey to have that experience.

Aubrey:  
It was called Leader Dogs School for the Blind.

Aubrey's mother:  
In Detroit.

Aubrey:  
What was that?

Aubrey's mother:  
In Detroit, Michigan

Aubrey:  
Yeah, near Detroit- one hour away from Detroit, Michigan. Rochester Hills, I think.

Aubrey's mother:

And Aubrey had a lot of hospitalization during that time, in which the dog could not participate with him in the hospital. I could bring him every other day for a two-hour visit so they kept their connection and bond, but I actually ended up being the caretaker. Be unharnessed. I had the leash, he had the harness, and we tried to survive through that, but actually the dog, you know, didn't stand a chance under those circumstances. So, The Leader Dog School said Aubrey was wonderful and that he could come back any time that he wanted another dog. So we're very grateful for the experience.

Aubrey:

But unfortunately, I went to an allergy specialist and found out that I'm allergic to dogs and cats. So that might be a part of the real problem.

Aubrey's mother:

But the building does have a dog relief area. In fact, it's right outside the window there, and we hear all the puppies and we get to visit with them in the building. It's wonderful. It's nice that if Aubrey wanted one, we could -- they were talking about giving the dog special medicine from the vet to help it not shed, and to get a short-hair breed and all this other stuff that we could try again. We'll see. One thing at a time, because he had a Helen Keller Cynthia representative come in September of last year, so it's taken from September to August to actually get him to Helen Keller.

### **How long will you be there?**

Aubrey:

About two weeks, but the evaluation periods, the time frame periods that they go by, according to their time frames and periodic reporting, reports that have to be made on paper, so to speak, is eight weeks at a time. But the two weeks is a mere- it's just for observation, orientation and evaluation.

### **When will you start the classes?**

I'm sorry, please repeat.

### **When will you start the classes?**

Sometime in the first weeks of August, right? In the month of August.

Aubrey's Mother:

Right, the two weeks, they'll assess him for all his skills, and then they'll tell us if he needs a sixty- thirty, sixty, ninety, eight week, however they're going to portion it. And It'll probably be the September semester, I believe, but he flew up with some mental health staff from Dr. Kimberly Mathis' group. He's a part of the community treatment team, at the Drake Building. So his job coach, Robin, took him up for a weekend visit, and they were just catered to, they loved it, it's a beautiful campus. I didn't get to go, but Aubrey can tell you.

Aubrey:

It's a very beautiful campus. I forget how many acres of land- of botanical gardens are there at the site, but I know that as you approach Helen Keller Center for the Deaf and Blind, you first see these stakes, which are about telephone poles high, both sides and they open up, and then you come into a driveway, and it's like a mile into the Center, and it's surrounded by like woods and bridges- little bridges, like mediaeval-type bridges and stuff, not moats and stuff like that, but it's very beautiful. It's right on the waterfront where the beach is. It's very beautiful.

Aubrey's Mother:

Actually, to backtrack- sorry to interject. When Aubrey was at college, he actually worked at the Cranberry Wal-Mart, so he was working on the farm with the family, he was working at school, commuting, and he was working at Wal-Mart, and his- he, I think, ran on fumes. His week's schedule was like, he was invincible. He could just run and run and run. but he also had, when he came to Pittsburgh after commencement, he worked at the Allegheny East.

Aubrey:

MHMR Center. Incorporated, as a social worker, as a- my job was Residential Advisor. I was there for two years. For the deaf MHMR dual diagnosed clients. They conversed in sign language, but because of my sight diminishing, I had to look for another job that did not require sight, so I was basically relying on the little bit of hearing that I have left. This is one of my struggles. But I- with the correction of digital hearing aides and the technology that's available for a person like me nowadays is astonishing- in other words, the impossibilities seem to be more possible.

**Isn't that wonderful!**

Aubrey's Mother:

I call him, you know back in the seventies, when they had the Bionic Man, with the laser treatments and the cataracts gone and the newly-inserted lens, he went through a whole year of eye operations, and Dr. Vicki at Eye and Ear Hospital was wonderful, and all his ear team at Eye and Ear Hospital is wonderful. In fact, he was supposed to get a cochlear in his left ear this seventeenth, but they're postponing it until he gets back from Helen Keller, so that he learns more about it and he can make a better-informed decision about himself and then in December, if he would like the cochlear, they are ready to give it to him..

Aubrey:

The only thing that- Excuse me, Mom, may I say something? I just wanted to add a note to that. I turned down the cochlear implant surgery for one reason and one reason only. That's because I would not be able to appreciate listening to music the same way as I would in the past. I'm a big music lover.

**Oh, yeah. Tell me why you wouldn't be able to appreciate it.**

Aubrey:

I could appreciate music, but it would take- it wouldn't be the same as being able to hear music with your own natural hearing. Even if it was degenerative hearing loss, so to say,

with your ears on a neurological level, the loss of sound, no scratch that- I mean with the little bit of hearing that I have left, I'd rather appreciate the sound, the natural sound, as opposed to synthetic noise.

**Yeah, I understand that.**

Aubrey's mother:

Well, we call it enhancement, and it would be digital, but it would be as close to hearing, so that if he would go profound, it would be that his hearing could be wonderfully restored, but right now he's borderline, so the residual hearing is hanging on. That's why we're testing every six months, to see that window where it would be good that his eyesight would help him with the retraining. You have to go once a day the first week every day, and then every other day, and then once a week, and then you know, it tapers off, but it's a whole year of fine tuning of the cochlears.

So that's where we're at now, because I waited thirty-five years for him to be able to go to Helen Keller and to have the eye surgery and the ear surgery, and just the thoughts that even Helen Keller didn't have these options to pick from is amazing, because when we were considering all the options and just letting him comfortably be his organic state, as neutral, or enhancing him, and the risk of losing that little bit of residual and causing profoundness to be too early, that - I'm glad he was old- and not in pediatrics when I had to make that decision. I'm glad he was an [-Track 5-] adult and could do that for himself. Because it's exciting, but it's scary.

**I know Kim Mathis, by the way, because we at the Department of Human Services, Allegheny County Department of Human Services, the Office of Behavioral Health, we have a task force on deaf and hard of hearing- it's the Deaf and Hard of Hearing Task Force and she chairs that. Have you been to any of those meetings?**

Aubrey:

Mom, could you answer that question?

Aubrey's mother:

He has been to some deaf-blind groups.

**But not this one?**

Aubrey's mother:

Yes.

Aubrey:

I do frequently go to what was formerly known as PHSDS, which stands for Pittsburgh Hearing and Speech and Deaf Services. Now it's Hearing and Deaf Services, HDS,- they abbreviated it, the acronym. It's in uptown Pittsburgh, and I go there for therapy because of my Usher's Syndrome deteriorating so rapidly and so badly that it actually came down to the diagnosis of me having some kind of psychosis diagnosis. Schizophrenia in general.

[-Track 6-]

**Let me ask you a little bit more about what you started to talk about. I guess it was the reaction to adjusting to losing your sight, that you got a mentalhealth diagnosis, right?**

Aubrey:

Yes, it's part of my genetic disorder that I inherited since birth. It's part of the- one out of every four males who have Usher's Syndrome will develop some type of mental illness.

**Really?**

Aubrey's Mother:

Yes, and at the age that he did. We're working with Dr. Mathis, who is sending his blood to be DNA-typed. They have now made nine categories of Usher's. It used to be Usher Type 2, and then it pushed him, his Mental Health into Usher Type 3, and so they want to be very specific on which type he has, so we know how to treat the prognosis with all the different methods. Exact diag- And a doctor in Ohio offered to do it for free, cause it wasn't covered by insurance.

So I mean ten years ago they didn't even have this test to offer Aubrey, so that's why we seem to be like too little, too late sometimes, with helping him, but it's as- everybody is learning as we go, and we're offering him as much as we can, but there's still a lot of need.

**Aubrey, what's the toughest part to deal with, the vision loss, the hearing loss, or the mental health issue?**

Aubrey:

Actually, the mental health issue, because without one's mind, forget about the other senses, forget about all the senses, actually.

**We hear that from everybody, by the way. I just wanted to see what your- if you were going to have a different answer because the mental health issues are the biggest, biggest struggle for people.**

Aubrey: Yes.

Mother: Actually, I'm going to ask Aubrey if I can share this first. Can I share a little bit about the hard times of the mental health issue.

Aubrey: You sure may. You sure may, Mom.

Mother: If I'm sharing too much, you stop me, okay?

Aubrey: Ok. It's okay.

Mother:

Okay. When Aubrey first got symptoms, his sister and I noticed. She would say, “Hey, Mom, Aubrey’s acting weird again,” and so we were trying to assess in our own amateur way how things were going for him, and so, of course, when Aubrey’s sight and vision crashed, both at the same time, he was about twenty-eight, he of course was depressed about it, and we thought he was going to try to hurt himself, so we- I had to 302 him to Western Psych. Well, that started us from the age of 28, to now say 29, 30, he was mostly in the hospital. He was north, south, east, west in Pittsburgh in every hospital psych ward you can imagine. He was in the 302’s and 301’s for a long time. He was treated roughly in the sense that nobody knew deaf-blindness, nobody knew his diagnoses, and they would all try new medications, and he was over-medicated and isolated, and I’m not going to say that he was neglected or abused, but nobody knew what to do with him –

**And this was- give me a year that this was.**

Mother: You were twenty-eight in what year?

Aubrey: The year of 9/11, 2001. I just happen to associate it with that date. It was a bad time for me–

Mother: Yes. Well, that was toward the end, but I call it my Y2K, because from 2000, 2001, 2002 we were struggling. We didn’t have Kimberly Mathis at that time, and thank God for the doctor and her efforts with deaf and blind people and her efforts with mental health issues. Because Aubrey was not happy in the hospital and not happy at home. He wasn’t happy as he was organically, and he was just not a happy guy.

So, to make a lighter note of the experience of the hospital and respite and all those things, Aubrey survived it because he met a young lady who was also hearing impaired, and they had a friendship. They had a wonderful friendship. She was over twenty-one. He was twenty-eight. It was Romeo and Juliet, I like to call them, because her name’s Julie, so I call her Juliet. And actually, like the Montagues and the Capulets, her Mom and I were duking it out, of course. So- but they managed to sustain a relationship from the Y2K period, to currently. It’s a little estranged right now, but they have a beautiful baby boy. And I’ll let him pick up and tell you-

**(looking at picture) Is that the baby’s picture up there?**

Aubrey’s mother: Yes it is.

**Oh, how beautiful!**

Mother: But it looks exactly like- dad and son, Father’s Day here. So tell them all about your dating, and your- that made him happy is my point. He went from severe depression and 302’s to wanting a normal life again, because this young lady was something that nobody else could give him. And that’s just what he needed, so God answered another prayer.

**Let me ask you- let me ask you for a minute though: Why different hospitals? Because you kept looking for a hospital that would understand the deaf, blindness, right? Unbelievable in 2001 that that's the case. But, that's my own personal editorial.**

Mother: I mean, I could name names, but all you have to do is pop out his file and you'll

—

**So, Aubrey. So tell us about this baby?**

Aubrey: I have a son. He was born November 16th. I can't keep track of his-the year he was born, but I know his birthday is November 16<sup>th</sup>.

Aubrey's mother: He'll be three this November.

Aubrey: So he'll be three years old this November.

**So he was born in November, you were born in November?**

Aubrey: I was born in May- May 20<sup>th</sup> 1973.

**Okay, I'm sorry.**

Aubrey: That's okay. Don't be sorry! That's alright. Say "oopsie", that's what my mom taught me.

Aubrey's mother: Yes, he was too apologetic, and I just said, "Well my favorite word in preschool was 'oops!' - try again".

**Okay, so he's going to be three.**

Aubrey: He's going to be three. His name is Patrick, and he bears my middle name, Benjamin, but he has his mommy's last name, Minihan.

**What is it?**

Minihan- M-I-N-I-H-A-N. He's a great boy. He's beautiful and he's smart, and he's everything that anyone would want.

**Do they live near here?**

I'm sorry?

**Do they live nearby?**

Aubrey: No, actually they live in McDonald, PA, in Washington Township- Washington County actually.

**So when do you see him?**

Aubrey: I will be seeing him tomorrow, actually, by the assistance of using Access Public Transportation. I have green tickets, which means it's unconditional, the prices are all for the tickets.

**So you'll be going down there?**

Yes, both ways

**Will they take you into Washington County?**

No, I go myself. I go from here clear to McDonald. McDonald is a city in Washington.

**But Access will drive you?**

Aubrey's Mother: It's right on the border, he just made it.

Aubrey: They go a mile-and-a-half radius past the border of Allegheny County.

Aubrey's mother: Actually, when Patrick was conceived, he was in a respite up in Polish Hill, Mr. Aubrey. He was doing a lot of dating, and that's good, and learning how to live on his own, not with Mommy, and that was fine. And his staff, Dr. Kimberly's staff, Kimberly Mathis helped him, but Patrick was a concern of everybody because of the Usher's Syndrome. And so with Magee Women's Hospital, we worked from the first sonogram at four months, with the doctors, giving them all the history we could, and we were afraid that maybe with Julie being hearing-impaired, too, she can see -- hers was a different diagnosis, the prenatal clinic gave us a fifteen percent chance that the baby would be deaf-blind. So we were all in prayer, and so far, the pediatricians for the baby say that he is perfectly normal, that there is no neurological impairment. But we know Usher's is sneaky. Aubrey has had DNA tests for the baby pulled and the mother and himself, and now we're getting a special test done, Dr. Kimberly Mathis is having this [-Track 7-]specialist in Ohio do, so that we know what type for the future, but his father's still alive. He's a doctor of chiropractic, and he remarried and one of his boys from the new wife is also involved.

**Do the mother and father both have to have the --**

Mother: I think they have to carry something that attracts the male thing.

**So what about Patrick's mother?**

Aubrey: She's deaf. She has hard of hearingness, but her vision is not affected.

**Is she- is her deafness genetic?**

Aubrey: That's a good question. I think she's the only one in her family who has it.

Aubrey's mother: They're still researching.

**And your daughter is fine?**

Aubrey's mother: My daughter's fine. She has excellent vision, in fact, with my old age, I have bifocals, and so she has to like read the fine print for me, and she is a nursing student in the Surgical Unit of Magee Women's Hospital. She's been there ten years, and they're actually paying for her education, and she will be done in about a year-and-a-half, now, cause she's working and school, and she's on the Dean's List like Aubrey. I've always been so grateful – both children have had the education because of being able to succeed, so I myself only have high school, but their father finished his doctoral and became a doctor, and Angie wants to be a surgical RN with neo-natal, and then of course, Aubrey wants to get his higher education in Law, so I'm pleased with all of them.

**Absolutely.**

Aubrey: I have a good friend of mine, who happens to be one of the only eight judges in the whole state of Pennsylvania, on a liquor board- State Liquor Boards. He's a judge, his name is Roderick. Rocerick Frisk. .

**I know that name, yes.**

Aubrey: In fact, he emailed me just this morning.

Aubrey's mother: He's his email buddy. They hang out.

Aubrey: He's a good friend of mine. He's legally blind himself, and was a student at Western Pennsylvania School for Blind Children, and he said if he can do it, he knows that I should be able to do it. He was offering encouragement.

Aubrey's mother: I was sayingg at his own pace. But this- all school in life is stressful, but you should be able to have enjoyment and the stress should be able to motivate you to do better, not that it should overwhelm you and discourage you–

Aubrey: Right. I have to be realistic, though, with my limitations, because if I don't, then I'll be an over-achiever. I'll just drain myself of all the energy I have.

**Aubrey, what's been the biggest struggle for you?**

I'm sorry, please repeat that.

**What's been the biggest struggle for you?**

The biggest struggle for me is to obtain my sanity.

**You are sane. You mean to keep it?**

I know, I need it!

Aubrey's mother: I think what he means is that when he was having trouble with his eyes, before the enhancement, he was a little visionary. He would see shadows that weren't there. He would see things that, you know, things that we would take for granted. Like say, an auditory noise, like the old refrigerator in his old apartment would pop every once in awhile, and he would think it was a drive-by, and that could be unnerving. And he could not hear the phone without the equipment we have now. He could not hear the doorbell. He would miss staff appointments. He didn't have an alarm, so he would miss his own appointments that he would get himself up for. So while he was struggling to be enhanced and have the equipment, which was too long of a period of time, I'm talking five or six years, he was struggling on his own, he was working within the system, he was heavily medicated, and it was just unnerving. He couldn't distinguish correct sounds. If people walking down the street would talk to him, he would be afraid, cause he had gotten mugged once or twice out on the street. In the EBO one time, these guys asked him for his wallet, remember?

Aubrey: Yeah. Well, I've had incidents happen to me. Some people take advantage of the blind. That's one of my struggles.

**On the other hand, what are you most proud of?**

Aubrey: What am I most proud of? My educational accomplishments, as well as my training that I got on Braille. I learned Braille. I thought I could never learn Braille. It was so hard at first. It was like trying to read salt crystals on the table.

**I know. I just told a kid yesterday- I think anybody that learns Braille is a genius. It's amazing, for sure. Especially when you could see! If that's all you knew is Braille-**

Aubrey: I use Braille mainly for labeling techniques, and stuff like that.

Aubrey's mother: Actually, to work with his computer, the Guild for the Blind, when it was back in Bridgeville, accustomed a two-week program for him that would cost \$5,000, but at that time Aubrey was not fully employed, or a full-time student, so they would not purchase it for him, so that's why we kind of muddled along with what we could do to keep his skills sharp, but now that he's going to Helen Keller, and now that I think they knew even ten years ago, a new kind of Aubrey, that he has the ability to perform with education at his own pace. It might not be full-time, but that they would give him the computer components he needs, like the Braille printer, and he would move from Braille I to the contractions and different types of new electronics that they have to offer.

**Well, Aubrey, who's been the biggest influence in your life?**

Oh. My professors from college, from Geneva, as well as my minister. in terms of my world view, the three questions, which are "Who is God?" "Who are we?" and "What is this world all about?" I believe that the world view, our ideology, if you will, defines who we are and shapes how we live, as well as how we affect others and ourselves.

**You know what, I'm comparing you, and I shouldn't compare people, but yesterday we interviewed a twelve-year-old with Ushers, and man, he was bright, and you're so bright. I keep thinking, "UsherWell maybe if you have Ushers you're just naturally a genius or something!"**

I think that is a compliment.

**I was thinking, too, that the importance of this project (that Judy brought forward) is the fact that his mother will be able to listen to your interview, and also about the mental illness part, something they can be aware When he's in his mid-twenties or late twenties.**

Mother: Yes. Because many doctors, when Aubrey was twelve, and fifteen, and eighteen, and twenty-one, even twenty-two and twenty-five, even the blind and the deaf doctors at Eye and Ear Hospital were not educated on that part of the extreme that the disease can go to.

Aubrey's mother: Right. At the age of two, Aubrey could hear a plane, a vacuum, a train on a bridge. He could hear loud bass, so he responded as to being a hearing child.

Aubrey: Low pitches.

Aubrey's mother: But until his maturity would let him be correctly tested in the audiological booths, which we had to practice a lot of games of empty bin with a block. And I would go, ba, ba, ba, ba, ba, and I would put three fingers on his throat, and I would put one on the jaw and one on the lip, and I would go, ba, ba, ba, ba, ba, and I would put it down when he heard me, so that when we went to the booth, when they tested him, if he heard it he could put the block in the bin, and so that's how we could do it. He was so little, he was just a little guy, and it took us from age two to three-and-a-half, actually go through a series of diagnoses, to find out that he had a loss of high frequency in this ear and that ear, and that he hears bass in men's voices better, and it was just amazing that it was so challenging.

Aubrey: It [-Track 8-] took me a long time to get accustomed to wearing hearing aids. I used to bury them in the backyard. My mom would have to go outside, put her ear to the ground and find the hearing aid, and the only way she could find them was the battery. I left it on and it would squeal.

(mother whistlingM

Aubrey's mother: One time he traded the neighborhood's little boy he was playing with for a toy, so I had to go down and explain to the little boy and his mom, and tell them that this needed to be returned. So he was quite-and one time from a taxi ride home from DePaul, they found it stuffed in the back seat of the taxi. We had to locate it the next day, and we had to search like fifty cabs to find out where his aid was, so we had adventures at first, but then he learned that it's importance, so within a year --

Aubrey: Oh I can't live without them. Assistive devices are very important for the handicapped, or for those who are disabled.

**Right. Have you been involved in any sports?**

Aubrey: In my earlier days I have, but I got a punch out of ... (?) for a big stomach myself-

Mother: Actually, he's a member of the BOLD of the Blind Outdoor Leisure Development, and he has actually been in the Pittsburgh Post-Gazette. Big picture of him water-skiing, and -

**So, Aubrey, do you think your mother's proud of you?**

I think my mom is very proud of me.

Mother: He is officially my hero, because from the age of fifteen to twenty-five, he was mostly at school, and just frequented at home. And I had to share him with the world, but that was the cost to get his mind educated, and to have him live the life that he wanted to live, as much as he could.

Aubrey: I'm getting to know Mom all over again for the first time.

As an adult?

Mother: This was our first year together. I just wanted to TLC him, and I know, my daughter says I spoil him too much and he shouldn't get too dependent on me, but we work it out. We pick and choose our battles, huh?

Aubrey: That's right.

Mother: Actually, because they found out at age fifteen, even earlier, twelve maybe, that he was a deaf-blind person, that I went up to the Western Pennsylvania School for Blind Children, and just decided to work any menial jobs that I could, and this has been the end of my twenty-third year there. I'm a para-professional and I work with deaf and blind and mental health issues, and also stomas and trachs, and ... fragile students. I love it, and I just call myself "the Mommy away from home Mom", because I've had no specialized training, except for my own son, and that which the school provided and I learned as I went. But the school's been very good to me, and with the support they have given me, I can relay that support to Aubrey, because it's a lot, it really is, and I'm already thinking, "Oh, God, he's going to go to Helen Keller and they'll find out what we haven't been doing or what we need to do, and I need to learn tactile sign myself, and Braille myself, and I thought, all those years at the school and I never was required to learn it.

Aubrey: That's okay. Don't worry about that tactile, don't worry about Braille- just learn sign language.

Aubrey's mother: You'll teach me!

Aubrey: Everybody's gotta know a little bit but she's gotta know a little more for me. I'm sorry, I'm teasing you.

Mother: Yeah, Actually, I have a book that's made for fourteen languages, so that if you travel, you can have the universal signs, so I'm learning. It's this think- like War and Peace. I'm learning.

**Tactile isn't so hard. Do you know who Rich McGan is?**

Aubrey: Yes, I do. He's a friend of mine.

**One of my proudest moments was when I was able to sign to Richard. Because I, and it was sort of like I was forced into it, because Richard was roaming around, and Access had just dropped him and his interpreter wasn't there yet, and so I was able to do it, and I thought, "This isn't t so hard!" you know. If you can finger spell, then you're okay.**

Aubrey: For the deaf and blind community, I went to a deaf-blind camping retreat in Seattle, Washington for leisure and recreational things to do. And they made a documentary called the Mind Travelers. They made a movie out of it for the deaf and blind. Yeah, I just wanted to throw that in there for whatever purpose it could service.

Mother: He's been to Seabeck for two or three visits. Three visits to Seabeck?

Aubrey: I went there about three or four times. A week-long retreat. Not in the city of Seattle, but out in the country of Seattle, where the mountains are.

Mother: Aubrey loves to travel, and it's getting more difficult for him to do it alone, because of his current medical diagnoses. But you like to travel. I've never been able to clip his wings. I said, if the Lord's going to do that, it will be a surprise, because he just wants to go and do, and it's hard to see him having to be back learning the ABC's and wanting to get his Ph.D. That's quite a jump.

**Ah, well, it'll happen.**

Aubrey: Yeah, one way or another. Anything's attainable if you want to make it to be that way, but you have to be realistic, too. I think the trick in life is to have a balance and not be so extreme on either side. Not to make a luke warm position out of it, either. Kind of having you face on one side of the spectrum or the other. Knowing where you stand, what your values are and what you believe in, and what is important to you in life, but be in the middle of it.

**It's a good philosophy.**

Mother: I think the one struggle that I face is, "Will I be able to have Aubrey at home in the future? Or will I, being at work or having to sleep, not be enough help for Aubrey?" Not that he would deteriorate, but can this situation be, like you say, permanent? Help

with his medicines, help with his doctors, help with his daily needs. Right now, we really are doing really well. It's working out for both of us, but as his needs would increase, I don't know if I would have to do the step aside again and share him once again with the deaf-blind community, and so that he -and we were talking to Dr. Kimberly Mathis about what is available for people with Aubrey's diagnosis. When he was in respite, nobody signed, when he was in respite, nobody knew about mobility and caning, and to do the safety things in the kitchen with the equipment, so that he could cook for himself, and so - the staff, they were very loving and they wanted to be helpful, but they didn't have the knowledge.

**You might have to share him with a wife? I mean, that could happen he's ja young man.**

Mother: Yes! I'm so ready for that because his older sister is thirty-seven, and she wants to have a baby, of course, before her biological clock runs out, being at Magee Hospital, she's in the perfect place, so they both made me really wait until I was very, very late in the game here for any grandchildren, but they're starting to give them to me. They're starting! But for right now the little that I can do to help, but I am ready for whatever the future can hold for him.

The one struggle is- can I say this? It's worse case scenario.

Aubrey: Sure, go for it mom.

Aubrey's mother: ,He can lose both eyes and both ears. His organic mental deterioration can increase, and his need for 27, 24, 8, 8 and 8, I don't want to say the word "Institutionalized," but his care will increase way way past what both of us are ready to accept.

**But that's not a given.**

Aubrey's mother: No.

**Don't even think about it.**

Mother: I'm not -- it's gone, it's gone. But anyone who's listening, whose child might have it, they said he would go blind at fifty. He went blind at fifteen. They said if he would lose, it would be like Alzheimer's, like the rest of us, you know, Lord forbid. But you know, we were talking fifties, sixties, seventies. Geriatric years. Well, it smacked him at [-Track 9-] fifteen, eighteen, twenty-two. By twenty-eight we were in crisis, and nobody was diagnosing him or prepared to handle it, so I don't want to be unprepared for anything anymore. No surprises, no surprises.

**So you're armed with the knowledge, but you don't have to expect it to happen**

Aubrey's mother: Amen, amen. I just really, really would like to see Pittsburgh not be ten years behind Helen Keller in New York, or not be behind Gallaudet in D.C., and not have to have our local guys go to New York and D.C. for care and, that Pittsburgh should

upgrade, and the OBR and the BBS should work together better, and there should be more facilities specifically for people that don't have to have the struggles, the experience of -- fifty percent of his struggles and hardship could have been avoided, and they weren't, so I'm not complaining. The people that cared for him were wonderful, but we could do, what is it? Good, better, best? That's what I'm aiming for. So I joined a NAMI group, the N-A-M-I Group, and I did the twelve step program, and I have been to several conferences, and I would in the future like to work more them, and they were, I thought I was all alone in the universe, so if there's any parent struggling, please go to NAMI. It's National Mental Illness. N-A-M-I.

**They have a very active chapter here in Pittsburgh.**

Yes, it was wonderful.

Aubrey: And it's good for you.

Aubrey's mother: You can edit this part out I went to the NAMI group and said, "I have a deaf-blind son, and they said, "No, we don't do deaf-blindness," I went-, "Well, if you won't let me come, where am I supposed to go?" They said, I had to convince them that Aubrey's mental health, associated with the deaf-blindness, would afford me a place in their circle. I had to convince them, because even that particular isolated group of specialists and parents and supportive staffing didn't -- it was the first time they ever had one of him, so I had to force my way into that group.

I have always been so quiet, and now I'm like the obnoxious parent. "Oh, no, here comes Paulette again!"

**What do you mean, you've always been so quiet? I don't know if I believe that!**

(laughter)

Mother: I don't know.

Aubrey: I'll drink on that one.

Mother: Oh, the parent I was when he was two years old, and the parent I am now, two different people.

**You learn, don't ya?**

Aubrey's mother: Yes you do, yes you do. So if I can ever share the story with a group of people, Aubrey and I would be glad to, so that's why we're wonderful to participate.

**How did you hear about this, Aubrey?**

Aubrey: How did I hear about --

**The project that we're doing.**

Aubrey: The project. In the community newsletter in the Morehead Towers. Through BOLD, B-O-L-D, Blind Outdoor Leisure and Development. I'm a member of BOLD and so is my mom.

Aubrey's mother: I'm a guide.

Aubrey: She's of assistance to me. .

Mother: Our first group BOLD project was Camp Conoquee. Yes, it was wonderful. We tapped maple trees, he went rock climbing.

**Did you go snow skiing yet?**

Aubrey: Yes, and water skiing, too. I was in the Post-Gazette for water-skiing.

Mother: Actually, Dr. Zimmerman was Aubrey's snow-ski partner.

**And Dr. Zimmerman is a –**

Aubrey's mother: He is a master's level visual vision certification program for staffing at one of the local colleges, I want to say Pitt. I'm sorry, I didn't – so remember Dr. Zimmerman?

Aubrey: Yes, I do, Aubrey's mother: Where'd you go?

Aubrey: Seven Springs. He was my first ski instructor, and I was a natural-born skier. It was second nature to me to go snow skiing. Not to brag, but I picked it up rather fast. I have good balance. That's one thing I like about myself.

Mother: Yes, he's very athletic. He loves to swim.

**So, Aubrey, is there anything that we haven't talked about that you wanted to say?**

Aubrey: No, I think, with Mom and I combined, with your assistance in interviewing, we've just about covered all the ground.

**Well, I really appreciate this, I really, really appreciate it, and I wish you a lot of good fortune with your son, and I appreciate your being here. Did you leave work to come?**

Aunrey's mother: Actually, I'm on summer vacation, since I work the school program, I have June, July and August off, and my daughter constantly reminds me, "Don't rub it in Mom."

