



Interviewee: **Kurt Kondrich**

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Interviewers: **Athena Aardweg, Judy Barricella**  
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**Kurt Kondrich**

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**Interviewer: Let's start with you giving us your name, where you're from and a little about your family**

Kurt: My name is Kurt Kondrich. I'm a Pittsburgh native. Born and raised in Pittsburgh. My whole family lives here. I've spent... I'm married to my wife Margie. Been married for 12 years. I have a 9 year old son. His name is Nolan and back in 2003 the birth of our second child Chloe, Chloe Emmanuel, and she will be turning 5 in two weeks. When she was born, we did not know at the time, but we were advised that she had the diagnosis of Down Syndrome upon her birth. I could go on. Since her birth, she is coming up on her fifth birthday, I've dramatically changed my life to better help and assist her and my family. Spent the first 20 years of my career as a police officer; it's all I ever wanted to do, when I was a little kid I think because you don't have to wash, I mean you don't have to match your clothes up. Uniforms are very easy to wear. And I like battling bad guys. Upon Chloe's birth I kind of became immersed in the whole system, as we call it. Early Intervention, the MR system, this system, that system. It became clear to me that the only way for me to get a real full understanding of this was to become employed in the system and work in the system. So I kind of made a leap of faith decision back in 2003 to leave my career, which I loved. I loved being a police officer. I worked a lot in community outreach and worked with kids in schools and I decide to leave and pursue my Master's Degree in Early Intervention. I currently work with the Director of Community and Family Outreach for Early Intervention Specialists which is a early intervention provider for about eight different counties. That's where my passion is, my passion has always been helping people and I just feel that Chloe has enabled me to take it to the next level and really looking out for and defending our most vulnerable citizens.

**Interviewer: So you were a police officer in the City of Pittsburgh?**

Kurt: In the City of Pittsburgh. I was a beat officer for many years over in the Bloomfield section, which is the Little Italy section. Everybody still knows me over there. I love working down on the streets just face to face and interacting with people. I just think it's the best way to connect with people and to help them solve problems and I was always up at the school when the kids were getting out. An interesting thing about when I walked the beat in Bloomfield, there was a house there for older individuals with diagnoses of mental retardation. And they used to come out onto the streets, there were four of them. There was Bob, there was Bill, Melvin and Jim. And they lived in this group house there and they would come out onto Liberty Avenue during the day and I connected with them. I started talking with them. Two of them were non-verbal and the other ones you could understand and we became very good friends. I actually bought them Pittsburgh Police baseball hats and I gave them to them and made them my deputies on Liberty Avenue and they used to tell me everything that went on basically. I used to take them to lunch at least twice a week. We would go to a pizza place, Angelo's Pizza

on Liberty Avenue. I met my wife on Liberty Avenue. She was a hair stylist over there- which you can't tell by my hair. I met her while walking the beat and on one of our first dates I said to her, "Do you want to come with me to lunch? You can meet my boys." And she thought it was a bunch of other cops and she said, "Okay, yeah, sure." So I took her to lunch and there was Melvin and Bill and Jim and Bob and we all had lunch together. And she tells me that's when she fell in love with me because she thought "whoa, you're hanging out with these guys". As a matter of fact Bill was at our wedding. We bought him a suit at the, uh... I was his confirmation sponsor over on Liberty Avenue when the priest wanted to confirm him. Point being this was long before Chloe's birth but I could already see the foundation being laid to be involved in this field. I walked the beat for years. I actually was on bicycle patrol, back in its beginning. I was one of the first bicycle officers. I did programs in the schools out in the East End with at-risk kids and kids that had issues just try to steer them in the right direction. It was neat, during that time I became connected with the John Merck residential center out there. They called our station one day and said they had some really troubled kids down there, would somebody come and talk to them? Of course my name came up. So of course I went down there and I started going there once a week, bonded with them. I actually got them Pirate tickets and we had a summer camp for them. So I really think God was laying the foundation for... So when Chloe was born in 2003 I was actually working, received a call, it was Margie and it was time to go. I rushed down and took her to Magee Hospital. When she was born, it was emergency C-section and the doctor leaned over with his mask on and said your daughter has characteristics of Down Syndrome.

**Interviewer: Right there in the delivery room?**

Kurt: Right there in the delivery room. My wife was still cut open; she was still... she was basically not very coherent at the time. Chloe was crying. They were working on, she had aspirated and he came over and said that and I know Margie, my wife, she just... she didn't really understand what was going on, of course. And I looked at the doctor immediately and they had her over on the table because they were clearing her and I said "Well, can I hold her? And I'll never forget, he said to me, "You want to hold her?" and I said, "Yeah, bring her over." So he brought her over to me and she's as beautiful as can be. I think she's the most beautiful woman around and I held her and that's where my journey started, really.

**Interviewer: Him asking you and being surprised that you wanted to hold her.**

Kurt: I could tell he was surprised.

**Interviewer: Because?**

Kurt: Because she was not... I still think, we've come a long way in the disabilities field, I tell people, I was born in 1963, if I had been born then with a diagnosis of Down Syndrome, it would have been a very sad time. I probably would have been sent off to an

institution and not even brought home at the time. So we've come a long way in retrospect but also we have, I tell families and I tell people, we have a long way to go of changing attitudes. My personal feeling is, working in the field and working just in society, is people still have this obsession with perfection and that everybody wants their child to be the movie star and I still think that is ingrained in people's heads. That's something I'm working to change. Maybe this doctor had an experiences before where a child was born with a disability and the family did go into a meltdown mode or "woe is me" mode. I know that does happen. I could tell he was happy I wanted her and I held her and sat there with her. That's probably why when she wakes up in the morning now she will not let my wife pick her up. She wants me to come and get her. My wife will go in there and she loves my wife but she says, "I want Daddy. I want Daddy." My wife says I baby her too much but I don't... I don't care. She goes to sleep, she still falls asleep on my shoulder every night. If you meet my daughter and say "Chloe where do you sleep at night?" She'll go "Daddy's shoulder." That's where she goes to sleep. So I don't, like I said... that's where our experience began. We went up to our room and, I will tell you this, we had some other, we had some nurses down there that kept referring to Chloe as the "Downs baby". I could hear them at the stations and that and I actually had to correct them that this is Chloe, this isn't the Downs baby.

**Interviewer: Which was really progressive for you**

Kurt: I've got to be honest with you, I just think because of my background long before that. I just think this was all being planned out. I have never seen people with, uh, never have, with disabilities as any different. I see them as, actually I think they have more sense than any of us. They have a lot more going on. They're able to disconnect a lot of things that keep us down in a lot of ways. I just... Our experience at the hospital before bringing Chloe home was, this was our second experience at bringing a child home, and the nurses weren't as upbeat and happy. They weren't coming in as much. We didn't get offered the steak dinner, the steak and wine dinner. They didn't even offer it to us this time (**TRACK 2**) and it was weird. It was almost like, it was almost like a mourning was going on there in some respects. That's where it comes back to the stereotypes of people still have and I had to really talk with the nurses a lot because my wife, my wife was not... She loves Chloe dearly but she was upset, because she didn't understand. It was a, it was a new frontier. It was a total new, um... Both of us didn't know, we weren't experts in Down Syndrome. We had no clue about what we faced ahead of us. It was kind of just that type of atmosphere. First I remember when I called my parents to let them know that Chloe was born then with Down Syndrome. I just think people don't know what to say. Nobody knew what to say at first, you know? It was kind of like shock, it was kind of like... Just cause we're still there. We're still not there yet. So when the first members of our families came in that day to see Chloe, this was another thing. It was kind of downtrodden. It wasn't as... Nobody brought any balloons in or anything. I'll never forget, my brother was the first one, he brought a Raggedy Ann doll which was cool. The second day people were coming in for our families to the room and it was still kind of... I didn't like the atmosphere. So I will, I'll tell you this on tape here.

I smuggled a couple of bottles of wine in. And people were just sitting around the room just kind of just... I don't know. So I popped the corks off of them and I started pouring glasses of wine and my wife said, "What are you doing?" I said, "I'm going to have a toast for Chloe right now." I said, "If you're not happy she's in the world," I said "get the hell out of here." Then everybody just kind of lightened up and it was good from that point. But it was, um... I'll be honest with you we were very anxious to get out of there and get home and get things moving. And our first very positive experience at the hospital was when Chloe's doctor came to see her. And her doctor is Asian... Pediatrician. Her name's Dr. Kim. I love her. She knows me well. I'm gonna see her next week for Chloe's fifth. She came in there and just was... She was the first one to come in there and, it was really cool. She picked Chloe up and said, "Oh my gosh look how beautiful this child is. She has smaller eyes. Look how pretty I am, I have smaller eyes." It was just, it was all positive. It was... It's interesting. I speak to a lot of professionals and families now and I tell people your words, your 10 seconds, 15 seconds of words, can have a major impact on a family, on individuals. And her 15 seconds of words started something very good as opposed to... I can tell you to this day, there was this one nurse that was just kind of ignorant and rude. My wife to this day if she saw her she would probably whack her. Because her words, not many, but she always referred to Chloe as the Downs baby and this and that. We always say that the verbal pain is a lot worse than physical pain. I would rather somebody hit me than have my wife have these things in her mind for all these years. Anyways, so our doctor came in, Dr. Kim and positive things. And Sheila Cannon came over from the Down Syndrome Center of Pittsburgh while we were still in the hospital and was very uplifting and very motivating. She gave us some good advice. She said Chloe's, she's a baby. Take her home, she's going to sleep, she's going to eat and she's going to poop. That's what all babies do. So take her home and enjoy her, rock her to sleep and we'll get things going when we need to. But for the time being enjoy your child. And I thought that was, I thought that was great advice. To just accept that this is your child, you know? None of us know what our child, children are going to become.

**Interviewer: What's interesting to me is, Chloe is only going to be 5, and we think we're in modern times, you know? And that the people at the hospital were still saying such inappropriate things and acting so inappropriately. It's amazing to me.**

Kurt: Well, one of the nurses printed out from the internet some information about Down Syndrome. I have it somewhere. We just moved recently, so I have no idea where it is. It was all the worst case... You know how you Google something, it doesn't, it gives all the worst case stuff about Down Syndrome. And she left it in our room and I was like, I wouldn't even let my wife see it. And right now actually I'm on the board of directors of the Down Syndrome Center here in Pittsburgh. We're working right now to make booklets for all of the hospitals with all kinds of good resources and positive things so that when a family has a child with the diagnosis of Down Syndrome they can just replicate this and give it. You know, just copy it off, say here, you know, here's some information, some uplifting things.

But it's amazing that we are still at that point. No, I - I agree with you. That's why I say for all of the progress that we've made we have to be very vigilant to keep on people and not go backwards. It's a whole attitude of the medical community, I think, that's been ingrained for so long. But if I might say something, recently the American Gynecological Society came out with this statement recommending that all women have, all women have a test for a Down Syndrome child. And if you read the statement you can see that they are alluding to the fact so that they can make the proper decision. What disturbs me is it almost in some ways suggests that if you have a diagnosis of Down Syndrome, since we're so, we think we are so smart with our genetic testing, then you can do the proper thing which is to eliminate that child so you can try again to have the perfect child. And that's a fear of mine as a parent, a society, obsessed with perfection that we become, that we get to a point where are we going to have genetic testing for autism, are we going to have genetic testing for obesity, for depression? What's our message, to just keep telling parents to try again so you can have the American Idol or the quote "perfect child"? My message to families and people is your child is perfect. Your child is actually more perfect than you'll ever know. So I think that's where that comes from and I think until we change the attitudes of the medical profession, not all of them, I think there are awesome people there. But in general and society's focus on having these children who really, they only exist in a fairy tale. These perfect, perfect kids.

**Interviewer: Well these nurses, I'm sorry I keep going back there but I think it is very important for us to get this on tape because if somebody listens to this tape 10 years from now, maybe it won't even have changed in 10 more years. Were the nurses who were inappropriate, was it across the board or was it the older nurses, the younger nurses?**

Kurt: There was an older one... You know, "older", my age. In her 40's or 50's and then there was, there were a couple of younger ones, too, that had some attitudes. That had some, uh... You could tell... You can tell a person's heart. I always say, you meet somebody you know within a couple of minutes where their heart really is. And you know whether they're real or whether they're just putting on a show. And you could tell with these people where they really stood. I would say, you know, at least three of the nurses I wouldn't want around my child. You could tell that they, you could tell that their view of Chloe was almost like "why didn't you have tests?" I could almost feel that in them. You know "what is she doing here?" You know? And that's disturbing to me, that probably disturbs me more than anything. We've advanced so far. We've advanced in genetics. Let's face it we've got all kinds of things figured out we think. One of my biggest fears is the day we don't have any children with disabilities. It's actually a possibility some day with genetic testing and I always say "God help us" because I don't think people realize our children are here, to me they are here as a reminder of what is important. Which is unconditional love, which is helping people, which is service to the community, and service... things we are losing as a society. I look at them as a visual, as a physical gift to remind an often misdirected society of where they need to replace their

priorities. Family, like I said, love, commitment, devotion, things that just, any thriving society is going to advance on. Without that I don't care how fancy we think we are, how smart we think we are, how rich we think we are. We're not going to get any better with condition of life.

**Interviewer: So you took Chloe home?**

Kurt: It was the best!

**Interviewer: And she slept and she ate and she pooped and as she grew up did she have any health problems?**

Kurt: Chloe had some respiratory problems. She was in a hospital for pneumonia within her first year and she had the RSV virus. Chloe had very large tonsils and adenoids and children with Down Syndrome have smaller respiratory systems so that was impeding her. She was having sleep apnea. **(TRACK 3)** About a year ago she had her tonsils and her adenoids removed and it made a huge difference. I mean we had the best, I said we had the best cold season ever this year. She was really, it was great. It made a huge difference not only in her, um, her health but also when Chloe had her tonsils and adenoids removed I say it actually opened oxygen up to her brain. She's actually advanced cognitively. Speech wise she is able to define letters better now and articulate better because of that physical impairment. I was talking earlier to 'Thena earlier I said, you know, years ago children with Down Syndrome... Half the children with Down Syndrome have coronary problems, heart problems. The average life expectancy for a child with Down Syndrome 40 or 50 years ago I think it was age 9 as a life expectancy because they didn't fix any of that. They weren't seen as somebody who needed to be fixed so if you took half of those children died probably within their first or second year because of the heart issues. Now because of, and this is a very positive thing in medical, the advances in heart surgery surgery. These children have heart issues, they fix them and they're good to go.

**Interviewer: Did she?**

Kurt: Chloe did not have coronary, no. No heart issues. So just respiratory and other things. And you know, we took her home. It was probably about 4 or 5 weeks after we took her home we learned about this thing called early intervention which I had no clue about.

**Interviewer: Was that from the Down Syndrome Center?**

Kurt: Down Syndrome Center and also the Allegheny County Alliance for Infants. Excellent organization here in the county.

**Interviewer: Who hooked you up? I mean, who gave you that information?**

Kurt: When Chloe was born, when a child is born at a hospital they automatically connect you with the Alliance for Infants as a referral when the child has a diagnosed disability. And then Sheila Cannon works for the Down Syndrome Center. You know, she promoted what early intervention would do for us. So we, uh, I say we called the Alliance for Infants and they sent out a service coordinator who explained to us. And we had no idea and it's an awesome thing. I've promoted with them. You can have your child evaluated, in-home services, speech, PT, physical therapy, occupational therapy, developmental therapy. In your home, it's free of charge. It's an entitlement program through the county for families in the state. It's an absolute blessing. My wife and I were like, we're going to go for whatever we could get for Chloe. These are the foundation years so we actually... Chloe began early intervention I'm gonna say 6 weeks after her birth, really. And it was really... It was great but it was also stressful. And the point is we had 3 to 4 therapists in our house 3 to 4 days a week for 3 years. And that sounds, well, that's great but you also have to think well it was very much a disturbance of our pattern of living. At the time our son Nolan was 4. And that's another thing I didn't say. Nolan when we were in the hospital he was very, very confused because he didn't see it. This was his sister and he loved her. I've got pictures of him holding her. And when people would get upset and, um... Even some family members were upset and crying and that. He didn't understand it. He was actually like "What's... this is my sister. What are you upset about? She looks great to me." And she still looks great to him. So it was kind of neat. Children teach us a lot of lessons about things. So we began early intervention services and like I said it was an interruption of routine not just for us but also for Nolan. He didn't understand what these people were coming to our house for. Who's this person, what are they here for, what are they working with Chloe? But what was neat about the therapists that we had on our team, they always incorporated Nolan. I've always said my son is 9 but he could probably be a PT right now or a speech therapist; he actually works with her with her speech. They incorporated him and that was the whole purpose of early intervention to get the whole family involved and excited about what they were doing. So we began the world of early intervention. It was during that time, my wife was very anxious about everything and just, you know. Worried about this, worried about the future. She would wake me up at 2, 3 o'clock in the morning, you know, uh... "What if we die tomorrow? Who's going to take care of Chloe? What if Nolan's wife doesn't like Chloe? What if Nolan moves away and gets a job in California? You know we're older parents and what if this? What if that?" So it actually during that time I started thinking about things and I actually was praying about things and I said "You know what? I'm going to get involved in the field." I had no idea how but, um... I was at a conference for parents. I got involved with as many organizations as I could with the time I had and I met a woman who is a professor at Pitt, Diana Knoll. During this conference she asked somebody, they asked me to come up and give their story and I said I will, I don't care. I'm not shy. So I gave my story and Diana Knoll said, "You ever thought about going back to school?" Well I said I did have a 4 year degree in criminology from IUP. I actually had an electric typewriter at the time, I was so excited about myself. I said "Diana, I have not been in school since '81." I said "I don't

think so.” And she goes, “I want you to come down to Pitt and get in the Master’s program” and I said, “I’m not Master’s material.” And she said no, and she kept bugging me which was a great thing. She sent me stuff, she emailed me and she was like “I want you down here.” So I finally filled out the application and somehow I got accepted. I tell people they felt sorry for me. They had to fill quota of old men with gray hair. So I went to the program... School of Education and I entered that. And at that point I left my career of 20 years being of police officer and began working as an education advocate for families and went to Pitt. I had saved money up over the years, I’m a pretty good saver, took some school loans. It was just a big, big leap of faith. I just really, you know, having a family back... I knew it was going to work out. I’ll tell you, I can remember the day I went downtown and handed my police stuff in and I cleaned my locker out. I didn’t tell anybody, because I’m just not like that. I just wanted to be quiet about this. Because I didn’t want anybody making a big deal about it. My wife was like “Oh, we’re going to have a big party” and I said “No.” I said “I’m going to take you guys out to eat tonight and that’s the end of it.” One of my supervisors saw me and said, “What are you doing Kurt?” and I said, “Oh, I’m leaving today.” And I just remember like, “What do you mean you’re leaving?” And I said, “I’m leaving. I have to move on. It’s just something I have to do.” It was... He was shocked but he understood. He was a dear friend. So I left very quietly. I’ve stayed in touch with my friends but it was... it was a big leap of faith for me. So I started going to school at Pitt at night. I used to, I used to work during the day at Achieva then I did practicums and I went to school at night. It was basically... I would come home at night 8:30, quarter to nine and then I would start my homework. Which lasted... I would always tell people, they get emails from me at 1:00 o’clock in the morning or 2:00. So I have no idea how I did it but I finished it in 4 semesters. I went full time. I remember them saying to me “Do you want to go part time or full time?” And I said “I’m going to try full time because I’m not getting any younger and if I don’t get this done, if I don’t just immerse myself in it, I don’t know if I can even stay focused that long.” So I went full time and I finished up and I now work in the field as a director of an agency in early intervention. I work directly with families. I was actually at a family’s house yesterday. Vietnamese family had a child with Down Syndrome and I went and spent a couple of hours up there with them, Just really... My goal is to really plant hope and optimism in families and to lift them up and share the positive stories and the good things that can happen if you, if you stay the course and access the services for your child. Yesterday was a really neat day for me. It was really neat seeing this family get excited when I left there and optimistic about their child. And I said what’s that worth in dollars, it’s priceless.

**Interviewer: What about your wife, she’s a stay at home mom? Has she always...?**

Kurt: My wife is a hair stylist and she cut back to becoming a part-time hair stylist after everything so we juggle our schedules basically. She’ll work Saturdays, she works some evening now. But we’re always, one of us is always there with our kids. That’s our, you know, that’s... you go through... I tell people that life isn’t a big party down here. Life is good, it’s a blessing, I enjoy life. But you have to work at things and you go through

stages in life. And we are in a stage now where we are really working hard on getting our kids focused and on the right track. As a neat side note, I just registered Chloe for kindergarten this week. Chloe finished up the early intervention system at age 3 and she did, it made such a difference. She is walking, talking, Chloe can sight read. Chloe can sight read a 100 words, just black and white words. We work with her. We were so excited when she left early intervention at age 3 we actually threw a big party at our house for all the therapists (**TRACK 4**) and we gave them all gifts and they were like “What are you guys doing?” I said “Well, you guys have given our family so much.” So we had a party and Chloe, Chloe is now finishing up preschool. She’s been in preschool for 2 years.

**Interviewer: In a regular school?**

Kurt: It’s an inclusion. There are kids that are typical and kids with disabilities in her classroom. And she loves it. She is just like “Bye dad” when I drop her off, you know, she don’t even like, she’s out the door.

**Interviewer: Where does she go?**

Kurt: Brookline, um... It’s over in Brookline. Brookline Regional Pre-K Program and it has been an absolute, excellent. I’ll give you a little footnote to that, I don’t know if the school wants to hear it but I’ll just talk off the cuff. This is what sent me into working as an advocate while I was at Pitt with kids with disabilities. I still do that now, I still represent families if they need help. On the day that Chloe turned 3 she was scheduled to begin the preschool program and the school district she was in at the time was doing some shuffling and her neighborhood school where she was supposed to be, when they counted the kids for the school they forgot to count the kids that were in preschool, the early intervention kids. So when the final numbers came down they realized they didn’t have room for our kids. This is another good example, they did not have room for our children. So the day we went to the transition meeting, we were informed that day that all the kids with IEPs, which is an Individualized Education Plan, which children with disabilities receive, were all going to be shipped up to a neighborhood that is not statistically safe, that is not accessible to families, it was out of our neighborhood. They were going to move our kids to Arlington Heights and all our families, nobody lives by there and some of these kids have physical things. And the parents, I’ll be honest with you, when you have a child with a disability and they are 3 years old... When Chloe went to preschool, she was tiny, she looked like a baby doll. You need to be close to them because you don’t know what is going to happen to them. They have mobility issues and such. But the school had made the decision to move all the kids up there and I’m like “What?” I was like, and the director said “Well, I’m sorry, Kurt, that’s what it is.” And I said, “Well, that’s not what it is. That’s not how it’s going to be.” They said “Well, we have 3 school board meetings coming up this week. One’s here in your neighborhood. And we have other ones, we know, that everyone’s fired up about stuff.” And she goes “If you like to...” I said, “I will be there, I will speak, and I will. Put me on the agenda.”

I attended all of the meeting. I kind of became the designated spokesperson for the family uprising. And actually the superintendent for the school district was at the one meeting and what I did is, I printed out... Being a former policeman, I printed out all of the crime stats for the neighborhood they were moving our kids, along with pictures of all the registered sex offenders in that neighborhood from the Megan's Law website. It was all free to the public. And then I put Chloe's picture and pictures of the other kids in the other side of the folder. I explained to him how you would not take the children who are the most vuln... First I asked him, I said "Do you not agree with me these children were the most vulnerable members of your school population?" and he did. And I said you will not move them to a neighborhood that is statistically unsafe, that is not accessible to the parents, who a lot of them have anxiety themselves. I said you are not going to do that and I said here is the reason why and I handed him the folder. Well I think I upset him but, you know.

**Interviewer: This was the superintendent? Of what school district?**

Kurt: Pittsburgh City School District.

**Interviewer: So was this Roosevelt?**

Kurt: Yes it was him. So I handed him the folder in front of a few hundred people. And he said "What do you want me to do with it?" I said "Take it back to your office and look at it." I said "You are not moving our kids." The Director of Special Education at this time had actually become a friend of mine. I spoke to her after the meeting and she said, "Well you shook them up." she goes. I said, "Listen, they're not moving our kids. I don't know what to tell you. I'll take it to the next level." I said "I'm not going to let go of this. It's not happening. Our children will not move. They will be... Whatever it takes. I'll go to CNN, Fox, I don't care. I'm not worried about it. I just... They're not moving my children, our children." So, it was interesting, we were going to the Outer Banks the next week and she said, "They're really taking this into consideration. They're going to make a decision next Thursday." And I said "Well I'm going to be down at the Outer Banks." I actually have some pictures of Chloe there that week. I said "I tell you what, here's my cell phone number. You call me." I said "I want to hear your decision so that I can decide what my decision is going to be, where I am going next." So it was Thursday morning at 9 o'clock my cell phone rang. I was sitting on the deck drinking coffee. And it was, and she said... What they did is, they actually formed a preschool in our neighborhood which has now become a magnet. It's a preschool for typical kids, kids with disabilities, they added a kindergarten classroom in there. They rented space at a Catholic Church that had a Catholic school that was, wasn't being used and it's just become, it, it's grown into an awesome school.

**Interviewer: And this is Brookline?**

Kurt: It's at Resurrection. It's beautiful. Parents are all... It's like our own... They basically get, we have our own little thing but it's nice, it's inclusion. And we have kids there. We have... It's safe for the kids. The teachers as you can imagine were as happy as could be because they didn't have to get shipped off to another neighborhood. So it was a great, it was an awesome, I say, advocacy thing and I use it as an example of the voice of a parent can make a difference. As I say all the changes that have happened to people with disabilities have come from families, have come from one voice, have come from somebody saying, "Wait a second, my kid doesn't belong in an institution. My kid doesn't belong to be separated. There's a lot going on in there you don't see." So that was kind of my introduction into advocating for children with disabilities and that kind of propelled me to where I am now. As an example of that, I encourage all families who have a children with disabilities to go see the movie *Horton Hears a Who*. Because it really was at the end of the movie is, they were trying to justify to the outside world that they even existed, as our kids do sometimes, it took the smallest voice in the community to break through and get the message across. And that's... Our kids have a small voice but it is very, very powerful and I think it makes a huge difference. So I actually take Chloe around with me everywhere. I've introduced her to legislators. I've introduced her to people in the community. Last year New York City has the annual, there's a Buddy Walk every year for children with Down Syndrome just to promote their inclusion in society and to highlight the things that they can do. New York City has the biggest one obviously. Everything's big up there. And they have a photo contest. They make a DVD that they distribute all over the country of individuals with Down Syndrome just doing activities. So I had taken a picture of Chloe reading a book under a tree when we were at the Outer Banks last year and the contest came up and I told my wife "I'm going to enter this with this picture." And she said "Nah, it's not gonna win, 'cause you got people all over the country entering." I said "I don't know. This picture is going to make a difference. I feel like it." So I sent it up to New York City and I got a, about 3 weeks later I got a call and an email that her picture was accepted for the video and it was going to be in it. And we were invited up to New York City September, the last week of September last year, last weekend. And what was really cool was we were in Times Square, right where the ball drops, and the big jumbo screen. I brought a picture to show you. We'll include in that in the things. You know, we're up there. And there's Chloe's picture up there in Times Square on the big screen. So my point being was she was 4 at the time and here's this little girl. The Post-Gazette and the Tribune Review wrote really big articles about it in the paper; really complimentary articles about people with disabilities. And it's funny, I have a relative... getting back to people's attitudes towards kids with disabilities, she's kind of, she's a sour person. We all have relatives like that, who we would rather not be around but because of blood relations we have to tolerate them. After Chloe's birth she was very negative and very kind of condescending and she is one of these people that are obsessed with perfection and that. It was kind of neat, this past Christmas we were all forcefully together. And she was bragging about something and I said, "Yeah, I said that's exciting but you know Chloe is 4 and she's been in Times Square on the Jumbotron." I said "She's been in the Post-Gazette, the Trib." I said "I'm just having a hard time figuring out what's next for her. I don't know, CNN was talking

about getting her like a spot as a guest commentator. I just don't know what's next, this kid, she's done so much for a 4 year old." And it was really neat to watch her face. I thought she was gonna, her ears were going to blow! Whatever. It was good because that is the message though. It is the message. Don't underestimate what our kids can do and what they can be. So that was kind of the, uh, culmination of some really good stuff last year up in New York City. Just standing... It was a magical experience, you know? It was very moving. Then we went up to Central Park and we had the Buddy Walk. I mean, we took Chloe... I love New York City. We took Chloe down to Little Italy, down on Mulberry Street and she's walking around and talking to people and I don't care what people say. I'm gonna put a plug in for New York City. I love the people of New York City. They are very, I think they're very cool. They are very accepting. I think they are very good people. We were walking down Mulberry Street in New York City kind of the area where the mob hangs out and there was this big biker there and he had tattoos all over him and he looked like a hit man. And Chloe walked by him and said "Hi, boy." And he looked down at her. I'll never forget, he had these goggles on and stuff. He looked down and goes "Hey, you, come here." **(TRACK 5)** So I took them and like "What? What does he want?" And he took Chloe and put her on his Harley, and this was like a \$25,000 Harley, he took his goggles off, that were very expensive goggles and put them on her. And my son was standing there, Nolan, and he goes "Is that your brother?" and he goes "Yeah" and he grabbed him and put him on the Harley and I took a picture of them. He said, "Take a picture of your kids down in Little Italy on a custom chopper." And I just thought this is inclusion. This is what we worked for. And I said if you looked at that guy you would think that guy is tough, mean and miserable. He had a bigger heart than some of the people in the hospital. He had a bigger heart than some of the people you would think would had the big heart. He understood what it was all about. That's another message, don't judge somebody by how the look or what they, you know, what they're wearing or if they have a tattoo or whatever. Judge them by what their heart is and what they're, uh, how they connect with people and how they treat people who are really the least of our brethren, the people with the most vulnerability, and the people who are here to really show us what's important. Chloe... You know it's neat 'cause it's five years. May 16<sup>th</sup> is her birthday so it will be five years in a couple weeks. We are having a party at our house and I look back at 5 years and I think if you told me 5 years ago, "Hey Kurt, I'm gonna let you know. In five years, you're going to leave your career, you're gonna do this, you're gonna do that." I probably would have 302ed you over to Western Psych and say "You're crazy. There's no way this is can happen." But it has and the battle will always continue. Also through Chloe I got very active with the state and trying to make changes. They have an advisory panel to the Governor's office that advises them on all issues of early intervention. And through my persistence I became a member of that. There are only four parents throughout the state who are members on that. I received a call a couple of weeks ago from Harrisburg and starting in August they actually want me to be the chairperson of the council for the whole state and it's kind of neat because it is the first time a father has ever done it. And the first time it's someone from Western Pennsylvania. I'm not sure it's something I wanted right now but it's not my timing again. So it's another great opportunity to

showcase. So I'm going to be taking Chloe to Harrisburg with me every other month and we are going to go walk around and we are going to meet people and we are going to put a face on who our children are and what they are and who all people with disabilities are. I really believe that's how we change attitudes. It's not through an email or a phone call, it's from getting out and meeting and connecting and communicating and seeing people, having a meal with them. Just like when I used to walk the beat and sit with these four individuals and having a meal with them and seeing what joy it brought to them – it was really cool.

**Interviewer: Are they still around?**

Kurt: Oh yeah. We're still in contact. Oh, absolutely. It was neat the one time Melvin, who had some severe delays and that, but it was his birthday so we bought him a cake from Patty Cake and took it over to the pizza place and we had pizza and, he loves sweets, but we had this big birthday cake in front of him and Patty Cake makes really good icing. Melvin was looking at this thing. We sang to him and we got done singing to him and I said "Well, it's your cake Melvin." And he just put his face right in it. And it was awesome. It was the best birthday party ever. I don't remember birthday parties at all for my family but I remember Melvin's birthday party. He enjoyed his birthday cake more than anybody ever. Like I said, the purpose of inclusion, the purpose of what we've struggled - it's really been a 40 year battle if you think about it- is for people to see individuals with disabilities. I'm eternally grateful for the older people who've had to blaze this trail before there were any supports available; before there was any acceptance from society. They are really pioneers. They are the people who, God bless them, because they laid down that foundation. They were the persistent ones who kept knocking at the door. When you think of people with disabilities and institutions and I think of Chloe and I think my goodness if this child had been institutionalized not that long ago what joy and hope would this whole world have been robbed of. And I look at the people that were institutionalized and I think what could they have brought, what could they have contributed? It's really more than we even can imagine what they bring to this world.

**Interviewer: So does your wife say "Go ahead, I'll take care of the kids."**

Kurt: I'm a disabilities junkie, an early intervention junkie now or whatever. She knows this is my passion. She knows that this is my life. I remember when I interviewed to go down to Pitt to grad school I remember the one woman, Dr. Kazmarek who is in control of the whole department. Louise, yeah, she has become a very dear friend. And I remember her talking to me and she said "Well, now if you... when you graduate how long do you plan on staying in this career?" and I said "Louise, I'm forty some years... until I'm dead." And she said, "That's what I wanted to hear." I said "I don't have it. This is it, this is very serious. It's like a ministry. This is very personal to me. It's my job. It's my passion." What's the old saying, "Love what you're doing and you'll never work another day of your life"? That's the way I feel. I'm doing some outreach now

down in Greene County and Fayette County now working and plugging some of those families into services they never knew existed and it's awesome. Because it's... Just going down there, and I go even with gas prices I go, and going down there and talking with people and getting them things and I'm shipping some stuff down there. It's like they just won the lottery down there.

**Isn't it amazing? We have a tremendous amount of services in the state and in this part of the state. Isn't it amazing how many people don't know about them?**

Absolutely. I go out to any community outing like the Pittsburgh Pirates are having a disabilities night and I'm going to set a table up over there. So we'll see you there, see if they win that game. I go everywhere. The Children's Museum. You know what's kind of neat? Last weekend I was at Magee Hospital. They had a Hey Baby Fair for new and expectant mothers. This is kind of neat. Chloe's state senator is Senator Wayne Fontana over on Brookline Blvd. and when I would take her to preschool I would stop by his office. I handed out some early intervention brochures and basically said if you have a family come in here that has questions have them call me and I'll help them, basically. I used to take Chloe in there and she would meet his secretaries and she lit the place up. They loved her. He sponsored this fair at Magee Hospital and traditionally in the past I can almost guarantee that I don't think they were looking for somebody as a representative from the disabilities community. But his Chief of Staff called me from Harrisburg and asked me to set up a table there at the fair. So last week I set up a table there and I can't tell you how many families I connected with. And the way I presented it to them was if you have issues or questions or whatever we are here for you and it was very, very well received. I was very optimistic about it. That's the way we are going to break down the walls. You have to go. I tell people if you are going to get into this field get ready to go. You're not going to be able sit around. You're not going to get rich but you are going to be making riches far beyond. I said I'll see them someday when I leave this earth. My pastor always says that the kids with disabilities will be the greeters in Heaven because they'll be the ones to remind people this is what you should have been focused on when you were down there worrying about your address and your car and your title. I'm a firm believer, like I said, for families to get out there. Take your children and other individuals and take them out and introduce them to people. Get involved. Like I said I go to all fairs and everything I can go to.

**Interviewer: Did you take Chloe and Nolan to the Children's Museum, they had a thing about 2 weeks ago?**

Kurt: The kids' party?

**Interviewer: Yeah, and there was a mural where you could do a picture on it.**

Kurt: The kids' party for the Parents Resource Network at the Children's Museum, it was an evening?

**Interviewer: No.**

Kurt: No, I didn't take them to that. But there was a kids' party for the Parents Resource Network and they were there going nuts. They were tearing the place up. And she does. I know some people have asked us, who don't understand children with Down Syndrome, they ask what does Chloe do? I say she knocks her brother over, she watches Barney videos, she plays, when we have her at the beach she'll be digging. She does everything that your child does and then some. She also teaches eternal lessons on things. We go to the Children's Museum... For her birthday coming up, my mom called me the other day, she said "What do you want?" I don't want any more stuff, that's one thing I definitely I don't want is stuff. So I said you can renew our zoo membership. I take them over to the zoo all the time. I think it's a real treasure. **(TRACK 6)** I tell people, right after Chloe was born we got memberships to the museum, the zoo, the Children's Museum all those things and that was a real neat thing. And not just a child with a disability but for any child it is important that they get out and connect and they see things and they smell things and they hear things. One of my dreams some day is to have Outer Banks... I call it OBXEI. Outer Banks Early Intervention. I'm going to make a respite down there for families. They can bring their kids down there, we'll work with them. We got the largest sand and water table on the east coast, which would be the ocean. Just a place for them to really connect and rest. Parents need a rest, they do.

**Interviewer: Could you do that like immediately because I could use a rest!**

Kurt: Well, I've got people who work for me. If you told me 5 years ago, things can happen, it's just a vision. Something about parents, parents go through raw emotion. I've been involved in this, obviously it's changed my life but I can still tell you my wife still has those nights where she will go through her cycles of anxiety and this and that. I said we are blessed. Unfortunately, traditionally, families with children of disabilities, a lot of times it rips the family apart and I guess that's why I got involved in early intervention. To get in there as quick as I could to plant some seeds to hold that foundation together so they can see what good things can come out of this if you work together and stay the course and stay focused as a team. That's vital.

**Interviewer: Is she going to go to the same school her brother goes to?**

Kurt: Yes.

**Interviewer: Will she go on a school bus?**

Kurt: Sometimes. We live real close to the schools, so we can, you know... some people ride the bus sometimes. Yeah. I mean... She's... Chloe's... Get out of her way. I mean she just, you know... She has a crush on a couple of boys in her preschool right now. You know what's really neat, there's a little boy in her preschool who, he has autism and

when Chloe started there when she was 3 this boy was non-verbal. His mom was, she was upset and I talked with her. I said give him time. Chloe just loves him. He looks like Nolan, he has the same look with his eyes, and she just fell in love with this boy. She would always sit next to him and Chloe talks a lot, she really does, she never shuts up, which is great. So she kept talking to him and talking to him and talking to him, talking. He started talking and his mother said some of the first words out of his mouth were "Chloe" and I really believe it was the peer interaction of her. He wanted to talk to her like who's this girl talking to me that won't shut up; I've got to finally talk to her. And I just think that's so cool. That's what it's all about. Whereas both of those, Chloe and this little boy would have been shipped off and now they're interacting and he's really, his speech has advanced unbelievably so. Really neat. I've met some of the finest people in my life in the last 5 years. Finest families, professionals, therapists. People you just hope to meet in your life's journey. I've met these people; connected with them. I wouldn't trade those friendships or relationships for anything. I always say that Chloe also is my BS detector, it's kinda neat. Because we live in such a fast paced society where all of us are way too busy for our own good. So what's cool about Chloe is that if I meet somebody I can tell immediately by the way they respond to her or treat her whether they are somebody I really want to have in my circle of friends or even have exposure to and that's a blessing.

**Interviewer: I want to shake your hand because that's same thing that happens to me. I know immediately somebody's character by the way they respond to me.**

Kurt: That's a great word, character. I judge... I'd rather be friends with a guy like that biker up in Little Italy. I'm gonna tell you something. That guy, I don't know if he's a hitman or what he was. But I'm gonna tell you, that guy had a good heart. I'd rather be friends with that than some multi-million dollar sports hero who doesn't have the heart or compassion for really what's important. I tell people this. You know, I know that so many people who are obsessed with their children growing up to be starting quarterback, playing baseball. It's a national obsession, I call it. Sports are great but let's be real here, it's becoming like a religion when people know more about the sports page than what's going on around the world. My son Nolan is a tall kid and he's athletic. He could probably if I pushed him and plugged him into 7 day a week training, which is insane I think, but I'm not like that, he's not like that and people wonder why he isn't involved in 7 day a week baseball and I say because he really has no interest in it. He plays with his friends in the neighborhood, rides his bike, he plays, that's what I want him to do, I want him to play. I say I'd rather my son grow up to be a carpenter or master plumber, living in the city maybe, driving a Chevy, but be a good man with character and treat people good then being starting quarterback for the Steelers, living in Fox Chapel, driving a Hummer, married to a super model. I said honestly that would scare me for him to even be involved in that. And they look at me like I'm crazy. Because so many of them, that's what they're looking for and I just want to say, "You don't know what you're missing. You don't know what you're missing out on. You really need to sit back and refocus your priorities in life." I can tell you that Chloe lifted my faith to an all new level. She

totally, she knocked our priorities to where they needed to be. And that is a blessing. You can only hope for these kinds of things in life. You can only hope for your other children to have character. Nolan just... My wife where she works at the hair salon there are some younger girls who are teenagers and Nolan is very handsome but he is very kind and compassionate and they are always kidding Nolan that they are going to wait for him because the guys today are so... losers and they are going to wait for him to grow up because he'll be a good catch. And he will be. I want my son to be a good husband, a good father, and a good man of character in the community. That's something we need. We need that desperately in this country. That's something that no politician, no political party is going to cure. I always say if our country could just go back to honoring commitments and looking out for people and having love it really wouldn't matter who was running the ship because things would go along pretty well. They really would. Conducting themselves in an honest manner and in an honest fashion. Like I said I think I've met families and I've connected with so many neat families and they are just fine people. Lot of them are going through... What's neat, too, I work with families as a developmentalist also in the field. And what's neat is I go into some families that are really emotionally charged at the time and one of the first questions families will ask you as I'm sitting there trying to navigate with them. They'll say, they'll be telling you all the things they've been going through and you'll say, "I know, I know." And they'll go, "How do you know all this?" And I'll say because I live it and we immediately connect. We connect in a neat way and immediately are able to really, you know, develop a relationship where they get powered. That's my thing, I want to empower people. I wish to God we had a president who had a child with a disability. I wish we had a vice president, I wish we had a governor, I wish we had more statesmen and that that had children with disabilities or a connection to them.

**Interviewer: That's what we are always looking for when we're trying to get legislation passed. Because when you're trying to get legislation passed it's like "Who has a kid? Who has something related to disabilities in their family?"**

Kurt: Yeah, exactly. Because then it becomes you open, hopefully you open your eyes. Hopefully you see the light, as the old saying goes, when you experience that.

**Interviewer: Let me ask you this, who supports you? You're out there helping everybody.**

Kurt: I'm very strong in my faith. I'm a very strong person of faith. I'm not, uh... people say "Oh you're religious." I'm not even really very religious but I'm very strong in my faith. My commitment to God and to why we are here for his service. I'll be honest with you; I've had a very good life. I've been very blessed in life. I've made some great friendships and that even as a police officer because of the way I worked as one. As a police officer I was about developing relationships and, you know, becoming part of the community as opposed to building walls up and that all has served me well to this point. I have some outstanding friends right now. Real friends, real people, people

you could call at 2:00 in the morning and they would meet you at Eat N Park for a cup of coffee or whatever. My brother, he's the Executive Director of an agency called "Beginning With Books" which promotes literacy in children. It's kind of neat, we are actually promoting his company with our agency and letting families know about the neat programs they have. He is a very dear friend of mine. He and I connect and we talk a lot. We talk every morning on the way to work, with the cell phones now.

**Oh, is that what people are doing? I think "Who are you talking to that early?"**

I'm talking... If you see me, I'm actually talking to my brother on the way to work.

**(TRACK 7)** You know, that's, um... He's a very dear friend. And my father has been very... My parents have been married 52 years. My father is a very dear person. I talk to my dad probably every day or every other day. He's always been there. He's stability. I really believe a man, one of the important things is a man, I call men to responsibility. When I see a man walk away from a family with a child with a disability, because of... and a lot of times, well, it's always selfish. I hear them say, "I can't take this" and I say, "You know what, you think your wife's going to take it when you walk away?" And I use this as an example because of my police background, I'm sure the firefighters when they pulled up to the World Trade Center on September 11<sup>th</sup> looked and there and most of them probably knew that thing was coming down. Most of them could have said, "You know, I can't take this today." But they took it and they went in there and they saved thousands of lives. People in wheelchairs; they got them out of there before that building came down. And I say, "You better take it because you are going to look back some day and you're going to really be a broken person for what you abandoned. Here's a neat thing about my father, my dad was from the generation where men didn't change diapers and really didn't do anything as far as with the babies, and he has 13 grandchildren but Chloe is his favorite. He holds Chloe and he talks to her and it's just neat to watch. He's 70... he'll be 73 this year so he's from the generation where people with disabilities were not part of society and it's cool to watch her influence on him. She has completely shattered any stereotype he might have had or perception that he might have had about a person with disabilities. That's the power of that small voice of that person and human contact. I think that society, talking about cell phones, progressives, and becoming more and more digital and I still think we have to become careful not to become so digital that we don't connect as human beings. If we don't embrace each other, if we don't look each other in the eye, meet and if we don't have a meal. Because without that it's all left to the digital world and that's the perfect world and we don't want to be like that. We never want to be like that. We never want to lose our emotions. It's good to cry. It's good to let things out. A lot of times when our therapists would come to the house back during early intervention especially for the first year, I know my wife would sit with them. You, know, I was at work at the time. But I know she would sit with them and probably cry for half the session. Not cry in a bad... Just cry to let it out. And working in the early intervention field I speak to therapists I say "Don't underestimate how powerful that is. Don't think that you have failed your session for the day by letting a

mother or even a father cry to you. Let it. If you are the conduit that is going to absorb that emotion and maybe allow them to get it out and move forward, then that's great that you're there for that." That's another big part of how we support each other in this field.

**Interviewer: They don't have to write in the report that this mom, we've got to keep an eye on her?**

Kurt: No, no way. Crying is actually very healthy. I'll be honest with you, if somebody is just stone cold stone faced, I get a little worried about them, to be honest with you. If a person is crying then they are real. They are experiencing something that is real.

**Interviewer: Is there anything that I haven't brought up or asked you? Who is your hero?**

Kurt: My father is my hero. Chloe is my hero. She has shown me what a small voice can do. She's changed the world already. She has. My family, my wife, they're heroes. My son's a hero. My heroes are the everyday people who work in the trenches, in the field, getting it done without accolades. I reference the fire fighters of 9/11. Those are my heroes. Those guys, \$50,000 a year they're making, trying to make a living in New York City, doing a job that most people wouldn't want to do, and that day it would have been very easy to walk away from what they had to do. But they are heroes. People who serve in the military, whether you support war or whatever, but the ones that go out and do a job, they don't make any money but they go out and do it. I remember when Patrick Tillman left the NFL to go serve and I really believe that in his heart was to protect people. And that's a hero, the people who don't get the praise, the people who are doing it. The therapist who's going into a house in the inner city, where most people don't want to go, to listen to a mother cry. That's a hero. That's a true hero of society. They are the people we actually should be reading about in the papers more often as opposed to the sports page and the movie page and Brittany Spears and who cares. American Idol. I heard a commentator say that most Americans were getting so dumbed down that they think that a good battle and a good fight is a series of Survivor. Real life people; a person who's a missionary. I person who's... I love baseball. I don't recognize the sport anymore because it has gotten so rich but one of my big heroes as a kid growing up was Roberto Clemente. I loved him. I remember going to see him. I went to the '71 series and I remember when he died. I was like 9 at the time and I was very, very upset. There's a guy who, back in those days, for his whole playing career these guys probably get paid that amount of money signing a contract before they even walk on the field. Roberto Clemente died trying to get supplies to a country hit with an earthquake. Flying in a, not in a jet, flying in a plane that probably shouldn't have been on the runway at the time. But he died doing that service. He's a hero. He's a real, you know... So heroes are every day people who go out there and make a difference and connect with people.

**Interviewer: When he died my dad was so devastated.**

Kurt: I was crying. I missed school that day, I was so upset. Cause I had his posters and...

**Interviewer: He was like a member of the family almost.**

Kurt: Well that was it, sports heroes back then used to connect with the neighborhood. And they never left, they played for the Pirates all their entire career and you knew them. You knew Ritchie Hebner liked Town Talk bread. Willie Stargell did a lot for, uh... Manny Sanguillen still does. They were here, they were part of the community. Whereas now, every year they are traded, traded. Teams leave cities. Like I said, they get paid more money to sign their name on a piece of paper than Roberto Clemente made in a career. Where is your priorities at? In the disabilities field we'll be fighting to get funding for a program and we're going to build a building in the North Side that legalizes the three most addictive behaviors known to mankind during a time when most people can't afford gas or food. I don't want to get political but its reality. That money could be served in such better ways toward, you know, planting a seed that is going to grow into something really beautiful. It just empowers me more, it just gets me whipped up in a frenzy and my wife tells me to calm down. Every time we go to family get togethers the guys will be standing around and they are talking about sports and that and I always interrupt them and start talking about something important and they look at me like I'm crazy. I don't care though. Maybe with one of them it will take. I really don't care about fantasy football, to be honest with you. I could care less about it. I'll take Nolan to see a baseball game. I mean, Nolan... One of my heroes, I love Nolan Ryan the pitcher in the old days but he's not obsessed with it. It fun to go and have a hot dog and a \$6 beer and he can have a \$5 coke and watch the game.

**Interviewer: Are you taking him to the game on the 24<sup>th</sup>?**

Kurt: Oh yes, the disabilities. Oh, yeah. He's going to help work the table with me. He's real involved. When he's out with a Buddy Walk and he knows what is going on. He knows his sister has Downs and he could care less. Nolan, I can see Nolan down the road. The kids in his class who are always kind of runts, the ones that kids might, you know... He always is like defending them. He's always like bringing them into the fold and I love that. I mean I love it. There was a little girl in his class who was kind of, she has a lot of anxiety, nervousness and she's shy and he's always nice to her. Two weeks ago she had a birthday party; he was the only boy invited. I said "Man!" It was neat. And she really invited him because he's nice to her. That was the reason she invited him. And I thought "You know what, that's..." And he doesn't even know, you know what I mean? I tell him, I compliment him and he doesn't know because that is just how he is. It shouldn't be something we even think about doing, being kind to people, (2<sup>ND</sup> CD – **TRACK 1**) treating a person with a disability for who they are, an equal and valuable person. That shouldn't be something you even have to think about. That's why we need to start getting people when they are young before their minds are ruined as they get older by the TV. My grandmother used to call it the boob tube. My grandma, God bless her. I

remember her when I was a little kid, this was back when you got three channels on a windy day, she would always say that the day the television came in the house is the day that Satan came in the house. Back then I didn't get it because there really wasn't much on TV but now I see where she was going with it. There's good stuff on, just like computers, but there's such much bad, so many distractions, so many things that keep us from doing, um, connecting. People used to go on Sunday and connect. You'd go and see your grandparents. You'd go see you aunt. Everything was closed. You were forced to go have a meal and we're losing that. And like I said, no politician is going to change that. We as people have to change that. We have to want that and desire to have that back and I think it would make a huge difference on our country's approach to everything.

**Interviewer: I think, you know, that might be one of the reasons. Kids are in the house, they're on the computer, they're watching TV whatever, where we were outside playing and we weren't doing that kind of stuff. When I was younger I used crutches and I was just outside playing with my friends in the neighborhood and they never thought anything weird about it. I think now we're not out as much growing up with kids and people still think we're different.**

Kurt: Our neighborhood we live in now, I love it. It's like a dead end street and everybody, there are a lot of young kids and all they do is play. My kids don't even watch TV. I just put a basketball net up this week. And the second Nolan gets home, I say "Do your homework". And then he is out. He is out until... And Chloe also. Chloe is connecting with the little girls in the neighborhood. They are so tired by the time they come in that they take a bath and they are out. They're sleeping much better now. They have no desire to be on the computer or watch TV or anything any more and I love it. I say it's priceless. I say it's the best ever and, uh... It's kind of neat, the neighbor we moved in to... The family that lives next door to us has a 4 year old child who has some developmental problems, he has seizure disorders and some other things going on. They're a young couple. When we moved in there and met these people they were just starting to go through some stuff and our kids have connected. Chloe – the boy's name is Drew – Chloe goes over there and just hugs him, kisses him and he's not vocal or anything right now, not really. And it has been so neat. I can just tell they are so happy that we are living there because we don't see their kid as anything but who he is. And Nolan's playing baseball with him and throwing a ball and once again it's that personal connection. And I've helped them already connecting them with some services and things. But that's what we do. We all go out as soon as we get home. I'd say there are probably 5 families. We all meet in the middle yard. Kids play. They ride bikes, they ride scooters, they swing. They just play, play, play. And you know, I might have a beer or a glass of wine and just chill there with my wife and it's, I think it's the best.

**Interviewer: Do you still live in the City of Pittsburgh?**

Kurt: No, we moved out. I was getting frustrated with two things. I was getting frustrated with, people say to me, “Oh you got that great preschool, what are you moving out for?” I say, “That preschool exists because we had to fight them. That preschool wasn’t given to us. That preschool exists... I don’t want to fight every year. I don’t want to fight kindergarten. I don’t want to fight this constant...” That showed me... When they did that to our kids, I’ll be honest with you, it showed me where their heart was. Once again. I had to fight them otherwise. I don’t want to fight them every year.

**Interviewer: What school district are you in now?**

Kurt: We’re in Upper St. Clair School District, kinda the lower end of it. I say Upper St. Clair, it like “Oh...” Our house was built in the 60s, it looks like a neighborhood in the city. I just happens to be geographically in that school district.

**Interviewer: Well let me just tell you as a mom of a special needs kid who’s now 21. You will keep fighting. You’ll be fighting through the whole education system.**

Kurt: Oh, I know that. I’m very aware but I will tell you this. One of the reasons I chose where we live right now, when I was an education advocate I had cases out. I got a taste of all the school districts and I had cases out there. And by working out there in the field I got to meet the Special Ed Directors, I got to question them, I got to see where their heart was. And I’ll be honest with you, the Special Ed Director in the school district I am in currently, she’s good. I like her. She has a heart for people.

**Interviewer: What’s her name?**

Kurt: Her name is Sharon Sharitzsky. And I’m going to tell you she has a heart for families, a heart for kids. She actually comes out once a month to families houses with her staff and sits there and has coffee with us and lets us ask her any questions. She advocates for us at the School Board meetings. I’ll tell you, you know what a busy time of year it is in the school year right now, I called her last week because my wife is having anxiety about Chloe going to kindergarten. I said “Sharon, you know, is there was any way I could just meet with you so my wife can meet with you?” And she meet with us within four days in her office with the school psychologist. Just sat down, let us air out anything we wanted. Then as we were sitting there she goes “You want to go up to your school and meet the special ed, the kindergarten teachers. I’ll introduce you.” I said “You have time?” and she said “I always have time.” She goes “Let’s go.” Got us in her car, drove us up there, introduced us, took Chloe around, made sure everyone knew who Chloe was and it really... It was like her saying this is one of my kids. See that? I know we’re going to have our struggles and there’s some areas where it’s more or less. She does it right. I compliment her. There was a big conference on inclusion up in Cranberry Township which is no where near. She and her staff were up there for both days. It was geared toward parents and advocates but she was up there and she was listening. So they’re not perfect but I don’t feel like I’m going to have to be printing out crime stats

and stuff and fighting every year. Chloe is in our neighborhood school. There's no question about it. They're welcoming. They wanted her in there. They want her in there. They said she was going to be a great part of the school. And it gave my... Another reason we moved, I want my wife to have peace. I don't want her to have to be worrying about fighting every year. Not that we're not going to have to fight but it's not as intense as what we have been through. I know that we are going to be fighting for all of our kids. That's what we do. That's why we are here.

**Interviewer: I'll tell you what, I was so glad to get rid of that knot in my stomach when my son finally graduated from high school.**

Kurt: Which school district?

**Interviewer: Shaler.**

Kurt: Oh, okay. I understand. See I understand. I got to know all of these school districts through working. And what's amazing, what's amazing and scary to me, is just even within Allegheny County, I mean, what do you have, 50 some school districts. You can go one district: not perfect but they get it, they understand, they really do welcome our children, they do try their best. But right down the road it's like you've gone through a time tunnel. I'm like "Wait a second!" And I've gone to them and said do you realize 5 miles up the road this is what they are doing. I've gone to school districts that don't even really understand what an IEP is; what a child's rights are with disabilities. That's scary to me because this is Allegheny County. What's going on in Fayette and Greene and out in the middle of nowhere? We've come a long way. There's legislation but getting people to follow it. I do believe a lot of districts will take advantage of a parent because by the time a child enters school a lot of times a family has broken up unfortunately. You have a single parent who's navigating raw emotions on a daily basis. They'll go in there and sign off on just about anything just to have it done with and realize down the road that "Wait a second, my child did not receive the proper education and supports that they really needed and deserved." And so that's scary to me. But I'll tell you, my daughter, they will know who she is. But that's unfortunate. It's unfortunate that I have to be that loud and visible. They're gonna know in her school district and she hasn't even started yet. In a positive way. I'm very polite and respectful to these people. I'm very complimentary. But squeaky wheel gets the grease you know. That's why when I'm working with families from day one I'm working to empower them. And as you said, prepare them for the next step of the journey. You go from early intervention to pre-K to kindergarten all in a 5 year period. Not to mention the birth of your child. Not to mention all the other operations and stuff. So in a 5 year period you are going through 4 major transitions and you have to really keep focused on what you are doing (**TRACK 2**) or you'll get swept away. Like my pastor always explains to me it's like a tree, you've got to get those roots down deep because the storms of life will come along. You might lose a leaf or a branch but at least you are still put, you are still where you need to be. But for most people the storms of life come along and the tree get

uprooted and blown down the road and that's what... I see that happen to a lot of families unfortunately.

**Interviewer: If you know Shaler School District you know Bill Watson.**

Kurt: I know all of the districts.

**Interviewer: I know, cause I had to threaten to sue him because he told me, and my son was, I home schooled my son for the first 7 years of his life because I had worked for Achieva. I worked for Achieva before they were Achieva. And I knew and I worked with parents transitioning and I thought "I just can't go through this" and I was fortunate enough to be able to home school him. But then he was old enough, he wanted to go to school.**

Kurt: To be around his peers.

**Interviewer: Yeah. So I put him in school, well started to put him in school, and I forget what I said to Bill Watson. We weren't even in the office yet, we were in the waiting room and he said, I said, "This is what I want to have done" and he said, "Well we can't do that" and I said, "Well you have to do that. It's the law." And he's like well, "No we can't do that." and I said "Well you are going to have to do it." And it was like "Oh man, what am I getting into?"**

Kurt: And you felt your face turn red and your blood pressure rise, kind of like I did when I did my preschool transition.

**Interviewer: Oh, I could have choked him!**

Kurt: Yeah, you do, it is raw emotion because a child with a disability, the one shot we have is to make them independent. Like I said, being an older parent my goal was for Chloe to be independent and accepted. So, God forbid... I told somebody right after Chloe's birthday, I was talking to somebody about fears and that and I said this is going to sound really crazy to you but my greatest fear is that my daughter outlives me. Every parent's worst nightmare would be the death of their child before them. And I know it sounds morbid but I hope I live to be a 100, I'm working on it. My greatest fear is me not being here so that I can kill somebody who messes with... Sorry to say that on tape. I will... So I can defend my child. That's it. That's my daughter. She's my princess. My greatest fear is not being here as her knight to protect her, watch out for her through life. That really is. Other than that, I'm cool. I'll be honest with you. I'm alright. It's all good. So therefore realizing that might not happen, the education system is only, it's one of the big pieces of the puzzle of getting Chloe embedded with the supports, the services, the knowledge that will enable her to be independent, you know? To be as independent as she possibly can. And that's a struggle, it's raw emotion. Like I said, I know my wife and I can't tell you how many times she has woken me up at 2:00 in the

morning, 3:00 in the morning. My wife has major anxiety and sleep disorder. I often wonder when we sleep anymore because we don't, we don't sleep normal sleep. But it's okay though. It's alright. I think God gives you extra strength. It's a struggle. It's a real struggle. But it's also I really believe in my heart with my faith that my child wasn't placed here, my child is a gift and I just have to constantly be working to unlock the gift that she is and that she is to others and showcase that. People who look at our kids in a negative light, I'm thinking you don't know if your child is going to get strung out on drugs. I know this from being a cop. Get in a really abusive relationship. You don't know what is going to happen and I tell people this too, "All of us are one car accident, one brain aneurysm away from being disabled and if you live long enough you will become disabled. So you should be very interested in what we are doing. This is the stuff I say at parties when they're talking about fantasy football. You should be very interested in what is going on in the disabilities field, what's going on with adults and children with disabilities because you're right there, you're right on the edge." You're, you know, um...

**Interviewer: You mean you're not excited about the Penguins?**

Kurt: Who do they play for? I'm not... Here's the thing about the Penguins and the Steelers. It's great, okay? It's great. If they win the Stanley Cup tomorrow, the next day... And I'm going to tell you an interesting story as a police officer I worked all of the Steeler home games. And I've got to be honest with you, and I hate to put this on tape, but I always rooted against them because if they lost, everybody went home. I was downtown in full riot gear during the 1993 Super Bowl and when they lost I was so excited because everybody went home. Because nobody came downtown to burn the city. And unfortunately that's the reality. People when they win I call Heinz Field the Temple of the North Side. It's like a sacred ritual out there to come and destroy everything and I don't... I don't buy into that. It's craziness. It's fun to go, it's fun to watch, it's exercise is great. But that's not the priority in it anymore. It's just about money and power and squashing people at all costs. Kinda like all the reality shows on TV. I don't like that, I'm not going to buy into that, I don't want my children buying into that. I had a neat opportunity recently. I was on WORD FM, which is a Christian radio station for Pittsburgh. I met the afternoon talk show host and I was talking to him about disabilities and telling him these things about our kids and he said "Do you want to be on the afternoon show and we'll talk about it?" And I said "yeah" and I went on and did an interview for about a half an hour and they let me talk. The Bible gives me a lot of peace and a lot of hope for things and there's a quote in the Bible in the book of Hebrews. You know back, two thousand years ago, you think people with disabilities have always been with us and I said 2000 years ago, if you look, you read history, people with disabilities were looked on as strangers. Well stranger wasn't what we see today. They were looked on as strangers because they were strange, they weren't normal then, they were acting different and they didn't look the same so they were cast out a lot of times from society. Most of them didn't live very long. And there is a quote in the Bible and I believe it's connected to this from when I've read it and it says, "Be kind to strangers for some have

unknowingly entertained angels.” And I use that. I say if you want to meet some angels come out and meet our kids. They may look a little strange to you but they look strange because they understand a heck of a lot more of what’s going on than you do. We’re the strange ones.

**Interviewer: What church do you go to?**

Kurt: I go to Zion Lutheran in the South Hills. It’s kind of, uh... We’re not really affiliated with anything, we’re open to everybody. The reason I love my pastor, he’s one of my dearest friends, and the reason I love him is, and he is one of my dearest friends, and the reason I love him is because he is out in the field doing stuff. When Chloe... When we went in to the hospital... This is a neat story. Margie was in labor with Chloe, it happened quickly. It was an emergency C-Section. I couldn’t get a hold of anybody and I had to take Nolan with us to the hospital. So I couldn’t get a hold of anybody, to watch Nolan, so we just rushed down to hospital. I got a hold of my pastor on his cell phone him and his wife, they were the first ones there. They came, I don’t know how... They’ve got 3 kids, you know, they’re busy. He doesn’t make much, he drives a Hyundai. They were at the hospital immediately to help us. They’re Chloe’s godparents. They actually went to New York with us last year to see the Time Square thing. What I like is he’s real. If there’s a family that needs something, this second. And it’s not about what religion you belong to. I don’t care whatever religion. I don’t if you’re Jewish, Muslim, if you need help we help. That’s what we are here to do. It was cool. We have a live nativity at our church during the Christmas season and the pastor during the sermon always he gets a baby from the congregation to talk about how Jesus was born. He was a baby, you know? And he used Chloe as the example that year and I thought that was kinda cool. Cause she’s who she is. I think there is an angelic type of connection with kids with disabilities. Kids in general, but the longer you live down here the more you get ruined by the society we live in.

**Interviewer: I asked you that because maybe a year ago I had a meeting at South Hills Assembly with the pastor out there and me (TRACK 3) and Vince Gaskin who was the county council person and we were talking about their various outreaches and they wanted to do more and it sounded like to me they were just starting to do community things.**

Kurt: I’ve gone there for concerts and things. Chloe loves music. She goes to Vacation Bible... What’s really neat about her is that she has a memory. She goes to Vacation Bible School and hears these songs like 2 or 3 times and she actually will be singing them. Chloe woke up this morning singing “High School Musical”. She must have been dreaming about it or something. We took them to see it when it was at the Benedum when it was down there, that was a cool show. It was really neat. Music is another neat thing. I really support music therapy for children. I think it’s a universal language that bridges all, all levels of development. I think Pittsburgh, I think we should be promoting our music here, our theaters, our orchestra, our symphony, that’s what we should be

promoting as opposed to pumping money into meaningless things. But I don't know. When I'm governor... I'll change that when I'm governor.

**Background Voice: One other thing, when you said you were a police officer and met your wife on Liberty Avenue, I wasn't sure!**

Kurt: The other part! That doesn't sound too good does it? Bloomfield Area. I'll tell you what's neat about Bloomfield too, we became such engrained in that community. When we got married we got our cake from Bloomfield, we had our rehearsal dinner in Bloomfield, we got our rings in Bloomfield, we got our shoes at Gordon's Shoes, we got our flowers in Bloomfield. And the guy who owns the funeral parlor, Winter's Funeral, I used to help him out with traffic, when we got married he... not the coffin limo, he sent us a limo over, you know, for our wedding. He goes "Hey, Kurt, what are you doing for a limo for your wedding?" And I go "I don't know yet. We're working on it." He said "Don't worry, I'm going to send the limo over." I said "Don't send the one with the, with the box in the back!" Cause he was a jokester, I figured, I said he would do something like that. So it was neat. I thought that was just kind of inclusion in the community. They really... just good people. People who don't really have much, most people living over there they really don't. That's not a... They give out, they give more. I guess this is another story should have tied in. When Chloe made the Buddy Walk in New York last year, they had articles in the Post-Gazette. And the Sister over at the Immaculate Conception School, she read the article about Chloe and she called me. Sister John has always had my home number. She called me up and said "Kurt, you know, the kids read this and we were sharing it." I hadn't been over there in years, 'cause you know. I went from the beat to... it had been years since I had walked a beat over there. It was early nineties. And, uh, she said our kids are raising money and these kids don't have much. They're having a bake sale. They're going to raise money and they want to, they're going to all do the Buddy Walk for Chloe and carry signs for her and they wanted to know if would go over and have lunch with us at Immaculate Conception. So we went over there and I have an article I can share with you. They wrote up in the Pittsburgh Catholic. It was so cool, these kids just, nothing. And they were baking cookies and selling them out on Liberty Avenue and that. And they made like \$600. They donated it all to the Down Syndrome Center of Pittsburgh and then they walked in the Buddy Walk for her. So, you know, their attitudes have changed. They will remember that, they always will. So it's good stuff.

**Interviewer: And not every kid that goes to Mac though is from Bloomfield?**

Kurt: No, absolutely not. Those kids are from all over. But traditionally, it's not like a rich... Their numbers have actually declined. Sister John has been there 40 years as the principal and we just became dear friends over the year. Just good people. I wouldn't trade my friendships and relationships for anything. For anything. They are what you carry through life and will serve you very well.

**Interviewer: So let's see those pictures!**

**Background Voice: Wait, I have a question. When you were talking about the Outer Banks, there's a whole sort of movement of social entrepreneurship like Strickland at Manchester. But I was thinking a place around here that wouldn't even need funding would be something close like Conneaut Lake. It's going under so why couldn't that be a retreat area.**

Kurt: That's a great idea. My parents met at Conneaut Lake.

**Background Voice: Yeah, it's local for a lot of people.**

Kurt: It's very accessible there. That's a great one. I'm gonna right that down.

**Background Voice: What I sort of disagree with you on when you are talking about getting back to the way America was and I'm not quite sure what it was. I was thinking that was more the myth of what America was. To me, what I think is happening is that people like you, Judy, Brenda are creating what America should be.**

Kurt: I agree with you, Tony. Like I said if you go back, I have a hard time believing that in America 40 years ago no one had the sense to see a person with disabilities that there was a very bright light there. I guess it was just out of convenience but they shipped them off to institutions. I think that is a horrible chapter that really is unknown. We know about the Civil Rights Movement, we know what other things happened here, why the Civil War was fought. But that in and of itself... That's why my heroes in America are not the politicians and that, they are the people doing to work, they're the people in the field, they're the people making differences, the people who are changing attitudes. Not just in this country but all over. When you leave America disability doesn't stop. It's a global thing. It's a global task we have. In some countries if you don't have a boy, women are still looked upon almost as a disability and in some countries they will abort the child because of their gender. That's a very scary slope we're on right there – God help us. Until the world has respect for human life in general and sees it for what it is as a priceless gift, we're not going to change things. If you took a Jewish child and a Palestinian child and an American child when they were little, they are going to play, they are going to bond, they're going to grow together. It's the adults that screw everything up. It is. It's the adults. It's people that make a mess of stuff.

**Interviewer: Well I'll tell you something that bring you right down. I read something in my email. I get this email newsletter from the American Association for People with Disabilities, it's called Justice for All.**

Kurt: You'll have to put me on that list, I'll give you my card.

**Interviewer: And one of their stories yesterday was there was a report out and I don't even remember because I was so appalled by this in a pandemic, if there should be a pandemic.**

Kurt: Oh, doctors will be gods. There was an article in the paper about that.

**Interviewer: No, that they'll let people with disabilities die.**

Kurt: That's what I mean. They are going to make the life and death decisions of who's important.

**Interviewer: We won't be the ones left because we won't be able to treat everybody.**

Kurt: Don't worry I'll be on your side. I'll be like Robin Hood. I would. I would never... That's what disturbs me. I get very disturbed by the advances. I've talked to people in the autism community and there is this big frenzied race to find the connection. And I say be careful what you wish for because once they find, if they find a definitive genetic code for autism that can be diagnosed in the womb, what do you think is the next thing? Actually the birth rate of children with Down Syndrome has gone down recently because they are not getting here. I have problem, I have a real issue with that. I can just see you walking into the doctor's office and in comes the genetic counselor and says these are all the genetic things they are testing for so you might want to try again. I know it sound crazy but I can see that happening with a society obsessed with perfection and obsessed with the wrong thing.

**Background Voice: Not so much obsessed with perfection, but obsessed with convenience.**

Kurt: Yeah, that's it, convenience. You're exactly right, that's a good word. Everybody just wants the perfect life. They want the, like I said, the perfect child. And that's where... I don't want to beat up on sports or anything because I think exercise and playing are great, but I don't think a child who is 6 years old should be a structured league 7 days a week where that is the focus of their life. There is a very small window (**TRACK 4**) of childhood. Let's face it once you get out of school and that, life don't get easier! When you start working and going to college and then you have a family; there is such a small window of childhood to be able to just play and to interact and to just let yourself go crazy and have fun and build things. We should be encouraging that as opposed to, I see so many structured activities. My goodness, these parents yelling and screaming at 7 year olds and I think come on now, give me a break. They're building, this is a neat project... I'll get on your email list. But in Cranberry, I just met a guy last week. He's building a field up there, it's called the Miracle League. It's going to be a baseball field for all children with disabilities, irregardless of disability.

**Interviewer: In Cranberry?**

Kurt: In Cranberry. I'll send you... It's really cool. I'm going to go to their next meeting, uh, Board of Directors meeting in June. Because every child should be able to play baseball. And I'm getting Nolan involved with that. He's going to become a buddy up there to help some kids. And that's the kind of stuff I want.

**Interviewer: Did you hear about the thing they are doing out your way some where. A friend of mine is involved. They are going to be teaching kids... bicycles**

Kurt: Oh, bicycles. I'll be there all week.

**Interviewer: Oh are you? Oh, good!**

Kurt: In Canonsburg; I'll be there all week. Lose the Wheels. Lose the Wheels. It's the something-plex down in Canonsburg. I don't know. I'm gonna be there. I'll be there for 2 sessions 5 days a week and Nolan is coming with me to that, too. Yeah, Lose the Wheels.