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*Erika Steuterman, September 2016, interview 038-mi, transcript, Indiana Disability History Project, Center on Aging and Community, Indiana Institute on Disability and Community, Bloomington IN, <https://indianadisabilityhistory.org>.*

**ORAL HISTORY INTERVIEW WITH  
ERIKA STEUTERMAN  
SEPTEMBER 2016  
INTERVIEWER: JENNIE TODD  
VIDEOGRAPHER: PEGGY HOLTZ  
RECORD ID: 038-DO**

**ES:** ERIKA STEUTERMAN

**JT:** JENNIE TODD

**PH:** PEGGY HOLTZ

[00:00:10]

**ES:** Hi. I'm Erika Steuterman and I live in West Lafayette, Indiana. I've always been a Hoosier. I was born in Indiana but I spent 18 years in Texas. So, I've gotten to see special education from Texas side and then back to the Indiana side. I was a career military officer. I spent 34 years in uniform. Most of it as a reservist solely because I had two children with disabilities and I could not see moving every four years getting the proper medical attention, behavior consultant guidance that we needed as a family and as an individual with disability. So, I have been fortunate that I found a way that I could continue working professionally at a very high level. I retired as a Major General or a two-star General. And yet when I wasn't elsewhere in Texas or Colorado or Germany or the desert, I could devote full-time attention to my girls and my siblings who also have disabilities.

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We moved from Texas to Indiana about 20 years ago primarily because we wanted a better quality of life and more safety for our girls. So, that's how we ended up at West Lafayette. Ron and I both got our undergraduate and graduate degrees from Purdue. So, West Lafayette was a known quantity, a very safe community, and we figured that we could find whatever services we needed there. So, it ended up being a very, very good choice. So, I have two daughters. A 34-year-old and a 30-year-old with intellectual development disabilities and two siblings. A brother who is 64 and a sister who is 59. Both with significant intellectual developmental disabilities. And I think I'll just call that I/DD from now on.

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[00:02:07]

**JT:** Perfect. Are you hearing everything?

**PH:** Oh, yeah.

**JT:** OK. So, Erika, tell us about the supports that were available to you. Supports and resources when you had children with disabilities. I mean you have obviously have had some family background and experience, but how those resources and supports have changed in the 34 years. Like what's available to young parents now as opposed to when you had young children?

**ES:** OK. The resources that were available to me when my girls were born were not very many. And that's changed significantly now 34 years later. We were living in Texas. I was on active duty in Fort Worth at Carswell Air Force Base and first of all, the medical care wasn't as good as one would hope for people who are full-time in the military. I think that's improved today. Right now the military is known for being able to take care of traumatic battlefield injuries, but taking care of day to day concerns with infants with disabilities, significant disabilities is probably still not the military's forte or the military medical systems forte. But back then I had absolutely no supports. I had no family that lived closer than 1,000 miles to us.

[00:03:33]

And they were, my parents were still working and they were happy to help when they could but they weren't readily available day to day. And I never got plugged into anything down in Fort Worth that would provide me any support. I remember when Erin, who is now 34, we had her first team meeting when she had just entered first grade. And my husband and I walked into this room and it was a literally an ambush. It was him and I against I felt like the entire school system. There must have been ten people around that table. Most of them whom I did not know. And that's when they said, "Your daughter does not fit into the system that we have. She needs to go into a special education classroom. Solely special education." And I remember walking out of that meeting in tears because I don't like being ambushed first of all.

[00:04:35]

There should have been a lot more communication back and forth between Erin's teacher and my husband and I. But he and I, we were young professionals. I had a huge job in the military as a, at that time I was a First Lieutenant, almost a Captain. I mean part of my job was arming the nuclear weapons on the B-52s. And I could get called at 2:00 in the morning and I had to leave to go and take care of national security issues. So, it was just really tough not having any kind of family supports. Nobody reaching out to say, "Here's what you need to do as new parents with a child with disabilities." Erin had seizures from the day she was born. And then we had some misdiagnoses too, which made a bad situation even worse where the military doctor said, "Well, we think that she has cerebral palsy."

[00:05:39]

And he told that to me when I was alone with him. I didn't have my husband available. I had no one there. And it was a shock to me. I knew something was wrong. But when he said, "And we're not sure she will ever have any kind of a life." Well, Jennie, you know what Erin is like today, and she has a great life. So, to be thrust with that kind of information that, first of all, wasn't correct was just devastating. And we insisted on getting another opinion from a neurologist downtown in Fort Worth. And that turned out to be better. The neurologist ruled out cerebral palsy. But it was still, it was still just a traumatic experience. So, I believe that young parents today have a lot more supports and a lot better supports. I'm on The Arc of Indiana Board and that is one of our top priorities is reaching out, first conversations with parents of young children with disabilities to help them know there is light at the end of the tunnel.

And you will have a joyous life. It may be a very challenging life, but it will be a joyous life. And I know that I am a much better person because of Erin and Jessie. They keep me down to Earth. They keep me focused. After spending 34 years in uniform, I was so, I have a servant's mentality. OK. I retired. I'm not wearing a uniform anymore, but, so what do I do? Well, now my focus is on helping families with young children with disabilities and as they go up through the school system, how do you get supports after age 22. And that's my focus now. That's where my service effort, especially community service effort is. So, it's much better. The school systems by law have to provide a lot more supports. My brother who is 64, he didn't even have special education to go to when he was young.

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And my sister who is 59, it was basically the beginning of special education in the public school system. And it was mainly babysitting. If the students who had disabilities ended up being alive at the end of the day, they had done their job. And that, there was no real emphasis on making their lives better, helping them to be more successful in life. It was, OK, let's keep Gina, my sister, alive until the end of the day and then we'll do it again the next day. And that's what was offered. That might be too pejorative of a view, but as a young person, as a sister who was only three years older than my sister, that's what I saw. And I do not know what my parents felt about the education that my sister got. That's something we just didn't talk about. It was hard for our family.

Me in the middle and then having two profoundly disabled siblings, that was hard for my parents and it was hard for me too. But I didn't know anything else. So, I supposed that made it easier in the long run.

**JT:** That was really good. Yeah. So talk about your siblings. And I guess I'd be curious, do your parents talk about it now? When you said they didn't talk about it growing up. It was just the way it was and it was hard for them, have they ever?

[00:09:30]

**ES:** Not really.

[00:09:31]

**JT:** OK. So [inaudible].

**ES:** No. But we can talk about their philosophy of sheltering me from that. I didn't become responsible for my brother and sister until probably 2009 or 2010 because my parents felt strongly that I needed to have my own life and part of that life was 18 years down in Texas. So, that was almost a given, but when I moved, when we moved up to West Lafayette, then I started seeing my brother and sister on a more regular basis. I would see them each at least quarterly. And then they would come up and visit occasionally. Usually I drove from West Lafayette down to Indianapolis. But my parents were really good about making sure that I had my own life with my own husband and my own girls. Little did they know I would have my own children with IDD.

And I really appreciate that now because the responsibility is all on me for my brother and sister. And I'm, I think that I can do a good job at that not only because I love them and they're my siblings, but I've had a good number of years to have my own life, my own career. I retired five years ago. So, I can be a full-time advocate for my brother and sister. And my dad passed away three years ago. My mom is 88, but she's very comfortable knowing that I will take very good care of my brother and sister. My issue is, who do I have to take good care of my girls when my husband and I go? That's a big, that's a big question for me and my husband. We don't really have any other family close by, nieces and nephews who have their own lives again and haven't dealt with people with disabilities.

[00:11:36]

So, that's my concern. I know that my mom is very comfortable that I'm the guardian of my brother and will assume guardianship of my sister when she passes, but what do I do about my girls? And I think that is something that all families with children with disabilities have to deal with, but usually, I would like to think that usually there is a sibling or someone close in the family who will assume that responsibility, and I do not have that.

**JT:** Well, you and I talked, and we're going to jump ahead a little bit, but you and I have talked about this in the past where you moved Erin into a house and you've got some trusts set up. And you've got some, you know, you've been thinking about this for a while.

**ES:** Right.

**JT:** And though you might not have everything figured out, you have somewhat of a plan because you are very plan [inaudible].

**ES:** Right. [laughing] I'm very deliberate.

[00:12:32]

**JT:** So, if you could talk about what you do have figured out.

[00:12:35]

ES: OK.

JT: That would be good to.

ES: This is what we have figured out for our two girls at this point. We are working on natural supports for them. Erin has a volunteer job. Excuse me. We're first of all looking at natural supports. Jessie has a volunteer job where she works at a Christian-centered restaurant. And she's developed some friendships with the ladies who go in there and quilt. I mean, it's not a group of people who are going to take care of her later on, but it's at least someone that's out of her regular day to day experience. It's not her housemates and it's not her family. They are other people. Erin has a very good support system at her job. She has worked at Purdue now, she started her 11th year, she loves it, and many of the people are the same. So, those are the kind of natural supports. I, again, they're not going to be helpful in an emergency, but they do give Erin a more natural life experience than what she would ordinarily have.

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Both girls have Arc Trusts. Arc Trusts II to be specific where they fund with excess money that they may have that can only be used for certain things. And it's easier to say what it can't be used for. It can't be used for shelter or for food. And it can't be used for buying gifts for other people. It's to make their quality of life a lot better. So, that's very important to them. Our youngest daughter Jessica was in a very bad car accident. She was a passenger. So, she also has a trust fund that has the same kind of rules as The Arc Trust II account. But in this case, my husband and I are trustees, so we manage those funds. So, I'm not concerned about Jessie ever having enough money. Erin saves money for what she calls her retirement. And that's what's going into her Arc Trust II account. Eventually I would like Erin to have an ABLE account.

ABLE stands for A Better Life Experience account that was federally legislated that, yes, you can have those. And when that becomes available in the state of Indiana, we will be getting those as well. Both girls have staff, DSPs, direct support professionals who we trust. Unfortunately, there are some regular churning of those. But the supervisors and on up in the chain of command so to speak have remained very constant. And there are some of those individuals who I know will make sure that Erin and Jessie are OK when Ron and I are either, don't know who we are, don't know who they are, or just aren't around anymore. A matter of fact, just a week ago Monday, excuse me, a week ago Sunday Erin was taken to ER for some issues. And Ron and I took her.

[00:15:49]

And when I followed up to her staff and her team at Wabash Center on what had happened, they immediately fired back and said, "All right. We need to make sure that Erin has the number for the on call person at Wabash Center so if you had been out of town, she would know who to call instead of just making that decision alone that she has to call the ambulance." She didn't need an ambulance. So, right there we saved \$1,000. And even though the mentality from a lot of people is, well, Erin wouldn't have

to pay that \$1,000 because she has private insurance and Medicaid and Medicare, the point is, the taxpayers like myself pay that \$1,000 ambulance ride. So, why not try to do it, if the circumstances are appropriate, have someone who you trust drive her to urgent care or ER. So, we have built some things in there to try to make both my husband and I comfortable that when they take our car keys away, the girls will be able to get the care that they need.

[00:17:00]

And I'm encouraged because I know I'm going to be around at least another 30 years. That plan will be cemented into place and there will be absolutely no worries.

**JT:** OK. Good. All right. Now we're going to jump back to your brother.

**ES:** OK.

**JT:** And life in Central State and your experience around Central State. Do you need a drink or anything?

**ES:** Yeah. I think I'll take a quick drink.

**JT:** And then we'll probably come back to this late life stuff at a later period.

**ES:** OK. Yeah. That's one I don't have an answer to.

[00:17:31]

**JT:** OK. So, you can start talking about Central State and your brother and that experience.

**ES:** In 2013, Wabash Center had their 60th anniversary of when it was set up by a group of concerned parents who wanted more for their children with disabilities than what the state and the local community would provide. So, I decided to start looking into the history behind my brother. He is less than, well, he's about 16 months older than me. So, we're pretty close to the same age. And I remember that he was a real handful. A really cute kid. He went to programs at Noble Center, or it was called Noble School back then. I remember when Roy Rogers and Dale Evans.

**PH:** Sorry. The, yeah, just don't have it in your hand.

**ES:** Oh, did I pick it up? I didn't even notice.

**PH:** [inaudible] You can move your hands [inaudible] it was hitting the...

**ES:** OK. All right.

**PH:** Sorry.

[00:18:40]

**ES:** I remember when Roy Rogers and Dale Evans came to Noble School. And my mom took me along with my brother and sister to see them. And there was a little gathering room with a piano. And Roy Rogers sang. And I had my little cow girl outfit on with my suede and my hat and all of that. And that was a

wonderful type of program we had. And I remember that specifically. And I also remember bad things too. I remember when my brother was sent to Central State Hospital and we would go visit him after church every Sunday and I was probably 10, 11, somewhere in that age. And I remember him coming out through the door of this big brick edifice because we were never allowed to go inside.

[00:19:44]

And he had, he had bruises all over his arms. And he had scabs. And I remember seeing these round scabs on his arm when I was a kid and I just knew that something evil was going on there. But I was scared and absolutely mortified. And I couldn't talk about it with my parents because it was, it was just horrible. So, I decided in 2013 that I was going to look into this and I was going to face it head on and find out what had happened to my brother. So, I contacted the State Archives because that's where all the Central State files are kept. And I had to get permission from my mom to go even though I was his guardian.

And I drove down there. It's in Indianapolis somewhere here. And I spent five hours. They had the files all pulled for me. It was all on microfiche. And they were ready for me. And they sat me down and I went through about 2,000 pages in five hours including a short break for lunch. So, as you know, I was reading very, very quickly. Skimming as much as I could. And it wasn't always easy to read because it was microfiche. And the stuff that I saw would turn my stomach. I remember those round scabs on him because one of the doctors' reports had on there that there were round marks on his hand that nobody knew where they came from. And nobody bothered to look into it.

There was no resolution to it. But to me they looked like cigarette burns. And I know that a lot more people smoked back then, and I suspect that they were cigarette burns that were all over my brother's arms. And the scratches and scrapes, those were from either the care takers or some of the other patients at Central State Hospital. And then I found this report that showed that my brother had received a concussion. He had been beaten so badly that he had to go into the clinic at Central State. And the doctor mentioned this. It's signed by the doctor. He's probably long gone, but that he received a concussion and they didn't know where it came from. And, again, there was never any follow up report or resolution on what had happened.

[00:22:50]

But who knows how much that affected him physically. He used to be a very strong young man. That's part of the reason why he ended up at Central State is because he was a danger to my family. But to be beaten to the point where you have a concussion, what does that do to you later in life? And being on all kinds of medications to do nothing but sedate you, what does that do to your life and to your health? So, I know that that was, that was horrible for him, but it was, it was horrible for me as a child knowing that evil things were happening inside Central State Hospital walls and I couldn't do anything about it. And then it was doubly horrifying as an adult to know that that kind of stuff was going on back then and nobody cared.

[00:23:58]

They didn't close Central State down until 1994. One other piece of information I found going through his files was the number of times that he was tied up. They had a whole checklist. That's what it was made for. They had codes on how they were tied up and how long they were tied up. Whether they were tied to their bed by their arms or by their legs or by both. If they were tied to their chair by their arms, by their legs, or by both. And how many hours they stayed there. There were many days where my brother stayed tied up much longer than he was not tied up. And that was just a regular way of doing business back there. And I really have a huge amount of disappointment that the state of Indiana didn't care anymore for people with disabilities than to treat them like a stray dog, probably even worse than how a stray dog was treated.

So, obviously I have seen a lot of improvements in how our loved ones with disabilities are cared for today. You still have to fight for everything you get, but there is no way that my daughters would ever have to deal with anything like that because they would have to come through my husband and me first. And fortunately, it has been outlawed. However, I mean, restraints, there's now, it's been legislated in the state of Indiana but only a couple of years ago about restraints in the schools. Restraints and seclusion. And The Arc of Indiana had a huge part in making sure that that happened at the legislature. But I just feel that my brother would be so much better off today if he hadn't had that kind of physical and mental abuse.

[00:26:16]

I mean, he listens to NPR and he talks about the Colts today and he knows country western music and he listens to NPR every weekend to hear the classical music. And he knows what's going on in politics. And imagine what he could have done if he had had the kind of resources and advocates available back then as my girls do today. He would have had a job. He would have been paying taxes. He would have earned a living. He would have had a reason to get up in the morning. Well, fortunately in 1994 when Central State was closed down, that possibility of having a reason to get up in the morning finally happened. And it happened, and it was good up until about 2010 when he started having health problems. Well, that's no surprise given all the stuff that the state of Indiana had done to him for 29 years as he was living in Central State Hospital.

[00:27:23]

But he was having some mental health issues. And once, it was in 2010 I went to visit him at, he was being cared for by a big provider here in Indianapolis. And I walked in, and I didn't see Steve. And I asked, you know, "Where's Steve?" And they said, "Well, he's in his bedroom." And he was sitting in his chair hallucinating. He was having a mental break and they hadn't bothered to do anything about it. They just kept him back in his room with the door shut. And I asked them why they hadn't taken him to the hospital, and they said, "Well, we'll probably do that on Monday." It wasn't a given. And that's when I said, "You are going to take him to the hospital right now, and I'm not leaving until you do." And that was something that they needed to do. And so we got him there.



[00:28:25]

We got him the proper medication. He was there for probably a month, and he started doing a lot better. And they were starting to take care of some other issues too. He was at the main hospital at St. Vincent's first while they took care of the physical issues, and then he went over to the stress center where he saw just fabulous improvement. And it wasn't long after he came back home he had to have his food cut up, soft mechanical, and he had to have somebody sitting next to him because he was an aspiration risk and they were afraid that he would get pneumonia. And the care provider didn't want to provide that extra manpower required to have the DSP sit next to him and oversee him while he ate his dinner. And I kept asking them about it.

I mean, they did it because they had to, but I got the 30-day letter that they weren't going to be caring for him anymore. And I also got a letter saying that they thought Steve would be better off with a feeding tube in a nursing home. That was their solution to, OK, instead of providing an extra person to watch him while he ate and to make sure that he was steady when he used his walker, we think it'd be better if he went into a nursing home with a feeding tube. And when I heard that, I called our lawyer, and I obtained guardianship overnight. That's how I got guardianship. And that's a terrible thing for a care provider to think is the best thing to do for one of their consumers. And I can't even believe they would have the guts to say that to me, to my face. So, after hearing that, the 30-day letter was almost a blessing and that's when I talked to the folks at Wabash Center, and they came down and observed him.

[00:30:35]

And I'll always remember Cheryl Harmon from Wabash Center who is now his case manager, on the drive back from Indianapolis to West Lafayette, she said, "We can give Steve a good home. We can give him a good life." And, boy, he was living up in Lafayette with two other house mates, and he has a very full life. And he still enjoys his food. Yes, it's now cut up in small pieces, but he enjoys life. He works in their sheltered workshop, which for him is an important peer activity and a social activity. And I don't understand the need to shut down all of them. There are some people like my brother who will never, ever be able to have a competitive job. And for him, he enjoys going there although he has told me that as soon as he turns 65 he's retiring. And that shows you how much is up there in his brain that was just left to die at Central State.

So, he has a very good life. And we see him at all the holidays. He only lives 20 minutes from me. He's a joy. For all that he went through, the abuse that he took physically and mentally, he is the gentlest person you would ever want to meet. And how he has developed that grace inside of him, I don't know how he does it. I would not be able to be the kind of good person that he is after experiencing 29 years of hell. But he's thankful for everything that he has. He smiles at people. He says hello. He wants to shake your hand. He's just a very positive person. And if that's a disability, then more people need to have a disability like that.

[00:32:47]

**PH:** Do you want to take a break?

[00:32:49]

**ES:** Yes.

**JT:** I was ready to cry.

**ES:** Yes. And I am so sorry.

**JT:** No. Don't be sorry.

**PH:** Now since the story of your brother, other people would probably want to know a little bit about your sister if you would want to.

**ES:** Sure. Yeah.

**PH:** You know where she, where here [inaudible].

**ES:** OK.

[00:33:10]

**JT:** But, yeah, I can't believe that if it hadn't shut down. There was no avenue to get your brother out.

**ES:** There weren't any services available.

**JT:** In '94?

**ES:** Well.

**PH:** What year, how old was he when he went into Central State?

**JT:** When he was 29 years, 29 years, so I guess it'd be 30 years from '94 so that would be like '60 something? [inaudible] like '65.

**ES:** Yeah. I'm thinking that I was in fifth or sixth grade when he went in. So, I was probably 11 or 12 when we were going out there every week. And it was just horrible. That probably messed me up in more ways than I can count.

**JT:** Your poor parents having to see that.

**ES:** Oh, yeah.

**JT:** You know, I mean, I just, I can't imagine. Well, OK. Do we want to talk about your sister now? Are you ready to do that?

[00:34:08]

**ES:** Sure.

[00:34:10]

**JT:** Ready to do that. OK.

**ES:** My sister, Gina, is about three years younger than I am. And she still lives in Indianapolis, and I am not her de facto guardian, but I serve as her guardian. My mother is still her guardian. She has given me responsibility. So, the only time my mother gets involved is primarily to sign the annual, her DSP, and things like that. Her plan. And she does come with me to probably half of the quarterly meetings. And especially the annual meeting, but the responsibility has devolved to me and it will be mine at some point officially. Changing guardianships ends up being a very expensive prospect. So, after spending \$700 and having nothing to show for it, I decided that we could just work it this way. But she has a, she has a good job.

She works in a sheltered workshop again. The type of work varies from week to week depending on what's available. And she enjoys it. She has a community guide who she goes out with. She goes shopping. She buys Christmas presents and birthday presents. She remembers everybody's birthday. So, she has a good life. And even though she was in the, she was at Central State Hospital. She was also at Richmond State and there's another one that she was at.

[00:35:46]

**JT:** New Castle?

**ES:** New Castle. She never appeared to have the type of abuse that my brother did. And I don't know why. Of course I haven't looked into her record yet. I'm almost afraid to go and delve into that. But she is doing well. And as long as she is doing well with her friends and her peers in her house in Indianapolis, then I think that's the right place for her. She comes up twice a year to have lunch with my mom and me and my husband and the girls. And we, I go down quarterly for her meetings and then I take her out to lunch if she's had a good quarter. Now, that is a little bit of an incentive because food is the center of her life that if she doesn't get to go out with me, she certainly will have a better quarter the next time so that we can go out to eat. That's a big motivator for her. So right now all is going well.

And when my mother is absolutely not able to deal with it anymore then I will assume the guardianship, but it will be transparent to Gina. It will be transparent to her team because I'm the one they already correspond with the most. So, it's amazing how much it has improved since the days of Central State and the other state hospitals.

[00:37:14]

**JT:** Well, and because they closed those institutions down, the options that families have would be to figure out how to provide supports to your folks or to your siblings or to your family to keep them home. So, things would look very different for both of your siblings in today's time don't you think?

[00:37:33]

**ES:** Yes. The way things are today, it would be easier to keep your child at home. Even an adult child. However, I think we're, the state and perhaps some parents are forgetting that it's really the consumer's choice of where he or she wants to be. That's why I dislike the name family supports waiver because it might be family supports. It might be living in a house in the community. I do think that families are better off when the parents can have a life of their own and when the consumer can have a life of his or her own. And if the parents want the child there and the child wants to be there, then that's great. But if the child wants to spread his or her wings and what child doesn't want to no matter how disabled they are.

They have a right to make that choice. And now we do have a choice. It's not either live with your family or go to Central State Hospital. You can live in a group home. You can live in a waiver home. You can live with your parents with support that comes in. There's all kinds of variations that you can do. There are choices. And I think that's what it boils down to. The person with I/DD needs to have choices. And they need to be helped so that they make good choices because there are always bad choices too, but they need to make their own decision. They need to decide on what kind of toothpaste they have. They shouldn't have a staff person who takes them through Walmart and says, "OK. Here's your toothpaste." No. That's a decision that a consumer can make without making any big error. So, why not let them choose what kind of toothpaste they want, what kind of body soap?

[00:39:36]

What kind of Kleenex they keep? Those are small things, but they mean a lot to a person whose decision making is really not there for most things in their lives. So, give them a choice when they can. And a big decision is where do you want to live? And that's why I have heartburn with people with I/DD who have been funneled into these county homes. There are only 10 or 11 left, but many times they were dropped there 30, 40 years ago because their family couldn't take care of them. Their families didn't have money to provide them a life elsewhere so they were dumped into these county homes. And I'm not saying they're not being treated well there, but, again, there's not a choice. And I know that the state of Indiana has not done its duty in making sure that people with I/DD who end up in county homes, which is not where they're supposed to be by statute, the state isn't making an effort to get them an opportunity to make a choice.

Do you want to stay in the county home? Or do you want to live in a waiver home or a group home?

[00:40:50]

**JT:** You brought up a very good point that we've talked to other people about. And this whole notion of even asking a person that. Do you want to live in a waiver home? Do you want to live with your parents? Do you want to live in a group home? If you don't have practice making those easy choices like you're talking about toothpaste, Kleenex, body soap, what you want for dinner, it's impossible to make a big choice.

[00:41:12]

**ES:** Right.

**JT:** You don't know the consequences of any of those choices. You don't trust your judgment. So, if you could talk a little about, just elaborate on the whole choice making that in order, like your daughters, in order to make an informed choice, they've had to practice.

**ES:** Right.

**JT:** That's something that a lot of professionals tend to assume, well I gave them a choice and they chose this. Well, these are two options that they didn't know anything about. And that's very different than the choice that you're talking about.

**ES:** Right. Making a choice to move out of the county home into a waiver home or a group home, that's got to come with a lot of background. You need to take them out and demonstrate, this is what it's like living in a group home or a waiver home. They have to be educated. And you're right. You need to start with the very basics. Choose your own toothpaste. Those kind of things. What are you going to wear today? When my daughters didn't want to wear a coat when it was 30 degrees I figured, that's their choice. If they get cold, they'll wear a coat tomorrow. But I'm not going to tell them what they need to wear. My oldest daughter, Erin, still dresses like a boy, and that's what she's comfortable with. Yes, I was disappointed 20 years ago when it first started, but right now I, and for some time I understand that's her. That's what she prefers.

[00:42:44]

That's what she's comfortable doing. And so I'm quite all right with it. I just want to make sure her clothes are clean. And that's the important thing. Are they clean? And is her hygiene clean? If that's the case? She can wear whatever she wants. And she can pick out whatever she wants. So, choices are very important. And I don't think we give our loved ones enough credit for being able to make a good choice. For instance, I remember when Erin was at, I think it was your first leadership building, and one of the first exercises we did, she said out loud that she did not like the fact that I redid everything that she did. Like when she made her bed, I redid it. When she set the table, I redid it. And that was the first time I had ever heard her verbalize anything like that.

[00:43:46]

And boy that was like a smack in the face. And I learned that it's her choice to make her bed sloppily and if it's not important to her, that's OK. I just close the door. I don't look at it. And now she's in her own apartment. I never see it. And it's the same thing. She internalized this and only when she was given a good opportunity to verbalize it did she ever do it. If it hadn't been for that program that you ran Jennie, I never would have recognized that I was doing that. And that is the wrong, that just takes the thunder away from anything they do. It's like we're always second guessing them. She does a good job. I always wanted it to be better probably because I have OCD. But how good does it need to be?

[00:44:41]

**JT:** All right. That's good. OK. So, I guess what I was going to talk to you about too is like you said Erica and Jessica have really good lives. And what sorts of experiences, opportunities, guidance, what has helped them have good lives? What has helped them, you know, get where they are? I mean, obviously you and your husband, but what other things along the way? You know, good transition from school to after school? What have been some opportunities that helped guide their success?

**ES:** The things that have guided our girls' success for their lives starts in the family obviously. But we can't take all the credit for that. We always made sure that they had great life experiences. I don't think it ever matters how much stuff they have, how many books, how many stuffed animals, how big their bedroom is. It's taking them out and having experiences with them. Taking them abroad. We took them both to Germany when they were nine and thirteen. That wasn't an easy thing to do, but they remember all those experiences today. You take them to museums. You take them to baseball games. You take them swimming, hiking. It's have experiences with them. Let them know that they can do a lot of things and they may not be the best at it, but they're darn good.

[00:46:22]

Erin started doing Taekwondo when we lived in Texas. And now she is going to be taking her test for her fourth Dan black belt. She has done very, very well. And that has really made her very confident in tackling everything in life because she knows that this is one of those little niche areas that she is very, very good. When she is taught something, she holds onto it and does not lose it. And that's why she is so good at her job. She learns something once, now it may take a while going over it with her, not only verbally but actually showing her how to do it. But once she has it down, she has it. And once you recognize that that's one of her skill sets, it helps inform what she could be doing in the long-term. She's had this skill set with Taekwondo for many, many years. So, when you go into working at a kitchen running their dish machine where it's repetitive work that has to be done right, that has to be done safely, she's perfect at that kind of job.

And that's why she's starting her 11th year there is because she is good. She loves her job. When Purdue happens to be shut down because of really cold weather or blizzards, the students are on campus. They still need to eat. And she is one of the few folks who always gets there. Now, it's usually Ron or me taking her into Purdue, but she is always there. She will not miss work unless she is very, very sick. And those are skill sets that a lot of regular people don't have that is needed in the workforce. So, if you can give them enough experiences so they have confidence that no matter what they tackle, it's going to be OK. And they have parents or loved ones behind them that are going to support them and not get after them if they make a mistake or do something wrong. That's what I had to learn.

[00:48:29]

Don't redo stuff because it's not wrong. It's just not what I would have done. That was a hard lesson for me but I wish I had learned it 30 years ago.

[00:48:40]

**JT:** Right. I think we're all guilty of that because my daughters have said similar things. It's, it implied that they didn't do it well enough.

**ES:** Right.

**JT:** And they're still, they're never going to do it right so why even bother.

**ES:** And another thing is having a good family life is always good. That's not a given. But you need to have a good advocate for your children. I have fired case managers. I have fired more people than I can remember because they didn't have the right attitude towards my girls. Especially towards Erin. I had one person who when Erin was in the throes of taking ISTEP, I sat down at a team meeting with Erin in the room and said, "She's never going to pass ISTEP." And I said, the first time I said, "Don't you ever say that again. Not to me and especially not to Erin because you don't know that." As it ended up, she was only a couple points shy of passing the math piece. At our next meeting, this lady said the very same thing.

[00:49:53]

"She's never going to pass ISTEP." And I literally had to hold onto the side of the table so I didn't go over after her. And I said, "You are not ever to talk to either of my daughters again ever." And I wrote a letter to the supervisor and I said, "She's fired." I got a letter back saying, "You can't do that." And I said, "Oh, yes I can. They are not seeing her anymore." And the next thing we know, we had a new person. She did much, much better. So, you can do what needs to be done. And sometimes it's not a pretty process. But as long as you keep professional about it and you're consistent, you're going to get what you need for your loved one. I don't care what age your loved one is. I mean, I still do that with my brother. If I think [inaudible] isn't going the way it should, I bring it up.

And it gets fixed. Or we'll get a new provider. At some point when I was having such issues with case managers, I finally decided that I didn't need to keep firing them because I wasn't ever going to get anybody better until my last one who is the best case manager, Cheryl Harmon, in the entire world with IMPG. She gets it. And but it took me years to find somebody with her skills, with her care and concern, and her love of making people's lives better. So, just keep getting rid of them and eventually you will find somebody who fits the bill and will do a good job for you and your family.

**JT:** So, tell me, do you need a break again? You want a drink or anything?

**ES:** Yeah. I'll take a little drink.

**JT:** How are we doing on time Peggy?

[00:51:56]

**ES:** 10 till 4:00.

[00:51:59]

**JT:** All right. So, I guess a couple other topics I wanted to talk about is their housing. You know, where they live and how they arranged the housing.

**ES:** OK.

**JT:** And if you think your daughters have a voice in their day to day life. And then what kind of conversations that you've had with your daughters about long-term planning as you and your husband get older.

**ES:** OK.

**JT:** So, do we have enough time to?

**PH:** Well, uh ...

**JT:** To do all that?

**ES:** I can truncate my answers. I mean, I tend to go on. I assume you're going to cut and paste it so that it's more cogent.

[00:52:38]

**PH:** And with Erin we do have, when we were at the Blueprint for Change, we do have the whole part of how she met with her roommate.

**JT:** OK. So, we have that one tape.

**ES:** That was Jessie.

**PH:** [inaudible] OK.

**ES:** Yeah because Erin doesn't have a roommate.

**PH:** All right. All right. So, that was Jessie.

**ES:** But I have issues with that. And I would like to explain that on camera.

**JT:** OK.

**ES:** Because this is a new twist.

[00:53:01]

**JT:** OK. So, we'll, we might have to just meet up with you another time if we run out of time because there are things I want to talk to you about.



[00:53:08]

**ES:** OK. OK.

**JT:** All right, so we'll start with the housing [inaudible] where you want to go for that.

**ES:** The housing for both girls has turned out to be very good initially. Erin is set for life. She lives in a retirement community, which she is able to live there if she has a disability. And she says she's going to live there for the rest of her life. So, she's all set. It's in a very safe part of the community. It has one entrance. So, it's safe. It's not outdoors. You don't walk from her living room directly outside. So, it's very safe. And she is happy there. Bus comes by, etcetera. Jessie is in a good waiver home. However, she has, she has improved and matured enough that she really needs to get different housemates. And it was her behavior specialist who came up with this idea that she needs to move some place where she can be more independent. Well, try getting that done. It's almost impossible because it's a domino system.

[00:54:14]

They had a housemate in mind where she and Jessie could switch. But then the person who she would be switching with didn't have a high enough budget to keep the current waiver home going 24 by 7 with coverage. And there's really no set process, any standardized process by which to find a new housemate who better suits your skill level and your independence level. So, right now Jessie is living in a waiver home. That although it's good, she is not going to be able to continue getting more independent and growing more in herself because she cannot leave that household. And that to me is really sad when you have an opportunity for somebody to take another huge step up and there's no way to do it because, first of all, there's no way to find other housemates that standardize.

And second of all, it's all budget driven. It doesn't matter that Jessie would improve if she were able to move. It's how do you have enough money in her home so that the other two housemates can continue to have 24 by 7 coverage because they stack waivers. I call it stacking where it takes three people to have enough coverage for one person for 24/7. So, that's something that needs to be improved. But it's not a bad situation. It's just that it could be better. And I always want to find something better for my girls.

**JT:** I guess I thought at one point you talked about buying a house or?

[00:55:59]

**ES:** Yes. We're still looking. We are looking for a house for Jessie potentially where she could have two other housemates who were at her level. But, again, there's no way to, there's no way to find somebody except if your case manager happens to know somebody. And I don't want to go through the expense of buying a house and then not being able to use it because she can't live there by herself. So, yes, we could buy her a home. That would be lovely and fully accessible, etcetera. But the housemate situation makes that almost impossible. But we're still looking and if something comes up, we might buy one anyway because perhaps things will change.

[00:56:47]

**JT:** Well, good. Do we have enough time to ask another question or do we?

**PH:** We can ask a couple more. I know you wanted [inaudible] get back too.

**ES:** I'm going to go shopping after this because I don't get to come down here and go shopping very often. So, I'm going to Clay Terrace after this. And if I remember they're open until 9:00. So, we can stay here until 7:00. OK [laughter].

**JT:** Peggy's son is playing or doing track.

**PH:** Cross-country.

**JT:** Cross-country. All right. So, your daughter is speaking up and using their own voice and getting people to hear them. Do you think, tell me about your daughters' experience. Do you think they are speaking up? And do you think people are listening? And has that changed through the years?

[00:57:38]

**ES:** As far as my girls advocating for themselves and speaking up for themselves, Erin has got it down pretty pat. If something is bothering her, she will tell Ron and me. And then we will help her talk to the right person, email the right person to get it fixed. If that doesn't fix it then I usually tackle it. But it's always Erin's responsibility to try to fix it first properly. And she's been pretty successful at that. When she wasn't, when they were going out to movies and they were going to see what the care provider wanted to see instead of what she wanted to see, I said, "You need to voice what you want to do, and if that person won't do it, then you need to tell his or her supervisor. And you need to let us know because if that doesn't change, then I will get involved, but you need to handle it first." And she was able to get it fixed.

But Erin is a lot more capable. On the other hand, Jessica doesn't have that kind of personality. And it was pointed out to me earlier this year when Jessie had to visit her pulmonologist because of that bad accident she was in. She still sees one annually. And when we got, I got there later than she did. But we went into the examination room later. The doctor came in who we know very well because he was with her for the two months she was in ICU. He said, "I need to tell you that my office staff said that her staff was screaming at Jessica on the way in to the waiting room." So, Jessica was being screamed at by her caregiver. And I was just flabbergasted. I said, "Jessie, you didn't mention this to me at all. Is that true?" And she said, "Yes, that's true."

[00:59:41]

And I was absolutely mortified. Believe me I hit that very, very hard. Jessie is not able to tell me when something like that happens. And that to me is very, very worrisome. So, that is something, unlike with Erin, that I really need to work hard on. "Jessie, these are your rights. This is how you ought to be and deserve to be treated. And you need to tell me when anything goes wrong." Now, unfortunately, sometimes what she says isn't entirely true. There are always two sides to every story and I recognize

that. But no matter what, she needs to tell me if something like that happens or if she falls and they don't tell me about it, which has happened in the past. So, that is going to be an ongoing project to get Jessie to stand up for herself more.

[01:00:42]

But that's not her personality. And I think that even if she weren't disabled, that probably still wouldn't be her personality. That's something that really worries me that she needs more outside oversight because DSPs are extremely important. They are the life and death differences for our loved ones. But they don't get paid anything. They have huge responsibility. And not enough salary to say that what you do is important. But they are vitally important to Jessie and Erin and my family. So, that needs to be fixed on a global basis that DSPs are recognized for what they do. They get the training that they need and they get compensated for making our loved ones have a good day and have a good life and be safe because I'm not there to do it.

**JT:** That's a key issue we hear everywhere.

**PH:** Oh, yeah.

**JT:** It's just a big problem.

[01:01:52]

**ES:** Yeah.

**JT:** Well, when you talk about the annual and quarterly meetings. Do you feel like there are persons that are thinking, persons that are planning that go into those meetings and that Jess and Erin are really prepared to say what they want to do and are supported to do what they want to do and that that's where they're heard as well?

**ES:** I believe that the girls, they think about what they want to say at their quarterly and annual meetings because I always ask them ahead, "Hey, how do you think things are going? Do you have any issues that you want to bring up at your team meeting?" That's very successful with Erin. Not so successful with Jessica. But, again, that's something that we need to work on. But I do believe the teams, each individual team does look at each one of my girls and think about them. So, I do believe it's happening. Erin is going to make it happen anyway, but Jessie has got that loving kind of team. The case manager, the behavior specialist, and some of the DSPs are very devoted to her and loyal to her. And they make sure that what they do centers around Jessie. So, I am encouraged with that. But, of course, that could end tomorrow.

[01:03:19]

**JT:** Do we have time for one more or do you need to?

[01:03:21]

**PH:** Yeah. Why don't we do the late life.

**ES:** Oh boy.

**JT:** OK. So, yes, the last question I was going to ask you was just, because this is something that a lot of parents, it's very taboo. You know, people aren't talking about their own demise. They are not talking about their planning. I mean, none of that like to do that. We don't even have a current will. So, people don't do this and people need to. And people need to plan. They need to talk to their family members. So, have you started any of those conversations with your daughters as to how things will proceed? And you have talked about the trust that they know certain things are set up.

**ES:** In the future, for when Ron and I are not around any longer or we're incapacitated, I have some comfort in that they both have trusts. But I have found out that it doesn't matter how much money you have, it's who do you have that is going to look out for their needs and spend that money wisely to make sure that they have what they need, a better life experience. So the money I thought that will solve all our problems. It doesn't, it almost makes even more problems because you want to get somebody in there who is not going to run off with it, use it inappropriately, whatever the fear might be. So, it's finding that person who you can absolutely trust with their lives whether it be family or outside the family. Whenever Erin does something that there has to be a consequence, for instance, if she misses the bus to go to work and she calls me and says, "Mom, I missed the bus and the next one doesn't come for a half an hour."

[01:05:13]

And I'll say, "Well, Erin, that's your problem. What if I weren't here? What would you do?" And she said, "Well, I would call one of my staff and see if they could come pick me up." And I said, "And what else could you do?" I mean, I make each time that there's a problem, I make it that she has to face the consequences. Yes, you could hire a taxi. It'll cost you \$25 but you'd have to take a taxi in. Now, when she most recently did it, it was right at the beginning of school this year. So, I went ahead and drove her in. And I said, "OK. The next time, you better have a Plan B because it may not be me." Same thing with going to the doctor. Or if she has an event that she wants to go to and she tells me about it two hours before the event. Well, I might be in Indianapolis. So, I said, "Erin, you've got to deal with it. I cannot help you. And there will be a day when I will not be able to help you at all."

[01:06:14]

So, I'm trying to make her especially understand that there are consequences for everything that she does. She knows that she is saving money for retirement and that she will not have any money issues when she's gone and the same for Jessie. But it's who do you entrust with their care? And that's something that I'm going to be working on for the next 30 years and probably until the day that I die. My husband and I are building our retirement home, and it's universal design. And we have built a room special that if one of the girls gets sick or can't live in their apartment or their waiver home anymore, we have a room that will be theirs. It could be for my mother too that there's plenty of room. It has the

closet and the roll in shower and all of that and everything that they would ever need is on the main level of the house.

[01:07:21]

And we've built it for Ron and me that way too. But that's kind of a Plan B for them so they will never have to worry about where they're going to live. Now, obviously, they don't want to live with mom and dad anymore because there are too many rules. But if push comes to shove and there are few options, they know that they will always have a home with us and it will be comfortable.

**JT:** Good.

[END OF INTERVIEW]