

Interview with a Texas Mother and Autism Advocate

*Interview conducted by
Nicholas Fields
In 2016 in Flower Mound, Texas*

Disability Studies Minor
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Biography

The interviewee, who wishes to remain anonymous, was born in Oklahoma in 1958. She attended high school in Abilene, Texas, then went to Texas Tech University. She became a paramedic and a fireman. When her son was diagnosed with autism, the interviewee and her husband helped to start the Denton County Autism Society. As part of her work, the interviewee co-wrote and pushed for the passage of a bill providing accommodations for Texas school children with disabilities. Though unsuccessful, the group helped to raise awareness of those with disabilities in Texas schools. She currently lives with her family in Flower Mound, Texas.

Topics Discussed

- Biography
- Autism Advocacy and Denton County Autism Society
- Proposed special education rights legislation
- Impact of the disability rights movement

Fields

This is Nicholas Fields, interviewing [Interviewee] for the UT Arlington, Texas Disability Oral History Project. Today's date is May 7th, 2016, and I am at her home in Flower Mound [a town in Texas, near Dallas]. I am here today to talk with [interviewee] about her work advocating for autism awareness. Thank you for participating in the University's Oral History Program.

Interviewee

You're welcome.

Fields

<topic>Biography</topic>

So to start, could you tell us a little bit about yourself?

Interviewee

I was born in Oklahoma. My dad was in the military so we moved a lot. And I went to high school in Abilene, Texas, at Cooper High School. I went to Texas Tech University for 2 years until I moved to Florida. I became a paramedic and a fireman. And then I moved back to Texas. Got married and moved back to Florida and then moved back here.

(We both laugh)

So bounced around a lot.

Fields

<topic>Autism Advocacy and Denton County Autism Society</topic>

What was the autism awareness organization which you wound up representing in the Texas legislature?

Interviewee

Really, we were representing individuals, particularly children, in education. It wasn't really a group. It was a lot of active parents. A lot of the rules for autism that are in the Texas Code now, at that time, they sunset [disappear] every so many years. And every time it would get ready to sunset, we would have to send out all these notices and get all these families, and parents and people to support that law...that rule, so that it wouldn't sunset, and we just thought that it was just exhausting to have to fight every so many years to keep these in place.

We decided that we would try and write a bill and get it into law so we wouldn't have to worry about this sunseting all the time. A lot of people who don't like supporting these kids have lobbyists, paid lobbyists, school districts, different health organizations. They lose money from certain things if these kids are allowed to have special schooling. And so, we felt like we had to kind of form a group to go up against these lobbyists, paid lobbyists, and so that's why we got involved to try and represent...most of these individuals can't speak for themselves and can't go to Austin to debate or to speak in public because of their disability. We were trying to be their voice.

Fields

How did this group come together? Who really got the ball rolling? And how did you become a part of this?

Interviewee

Well, my husband and I started the Denton County Autism Society back in the early '90s. And my husband was president, and I was past president or holding the position of past president, and we met a lot of people through meetings that we put on for this group. We had specialists in all fields coming to speak to parents and giving parents an opportunity to hear solutions that might benefit their children. We gave them an opportunity to talk to other parents about problems or troubles that they were having. I would answer the phone for the society and talk to parents who had just found out their kids had been diagnosed and help them. And because we had a son that was autistic and the problems that we had fighting the school districts and trying to get things that he needed to be successful, we met lots of parents who were having the same problems. We just kind of came together and said, "We need to do something to

improve the level of education that the kids are getting instead of them all being shoved to one room at all ages.”

Fields

<topic>Proposed special education rights legislation</topic>

What were some of the specific provisions of the law that you were trying to get passed?

Interviewee

Some of the main things that we really were hoping for was that you can't put a child in a situation without support structures in place. The child has to be able to succeed in whatever environment he is chosen by the school district to place him in. That was probably the most critical because placement always comes down to where the schools want to put the children. And if they decide to put them somewhere, but they don't give support systems around that child, they will always fail. It will always be difficult for that child to improve or get better. So one of the things that we had placed into this law was that there would be support systems to make sure that the child could succeed in his educational milestones.

Fields

You mentioned there was some opposition to this bill from different groups? What were some of the groups and how were they arguing against this bill?

Interviewee

The main opposition we had was from the school districts, because to reinforce... to enforce this law, if it had passed, it would probably cost them more money and so they're always opposed to anything that costs money, despite the benefit that it would provide for the child, the child's family and eventually the state. Because if the children are educated and trained early and able to merge into society better, it costs less money to care for them as they grow up and grow older. They were our biggest adversary at the time.

Fields

How was this bill and your group received, both by the Texas legislature and by the public in general?

Interviewee

Most of the public that we spoke with really supported it. They understood the need for provisions for kids with special needs who can't speak out in support of themselves and what they need. We had a senator: Senator Zaffirini, she was the sponsor. We had to have a sponsor for the bill.

The three people who wrote the bill were myself, Tim Cole, at that time he was the district Attorney of Montague County, and Anne [Zaffirini]. She also...we all had children with autism. And we sat down and started writing a bill, and then we got Senator Zaffirini to sponsor it.

And so when we went to Austin and spoke, when our bill came up, they seemed to...I mean...it's the political game. Most parents who have special needs kids don't have time...can't afford or can't find childcare long enough to drive to Austin and wait all day for your bill to

come up so that you can speak. And basically, what they did, you have to be there when they start so you have to drive up at six in the morning because you don't know where on the docket you're going to end up. And they kept pushing our bill back, further and further and so parents had to leave. We were almost the last bill of the day.

And they heard us...I don't know... I can't remember how many bills we heard that day, there were a lot, and most of them made little impact on daily life. I think one of the things they passed was a native lizard or something like that, you know, naming the native lizard. There was a group there trying to pass something about their football team. Probably the most impressive thing was; there was a group there trying to get a school implemented for kids in... to do...space training, and they actually flew Neil Armstrong in. We had to stop everything so that they could bring him in to give his support, which they immediately passed that bill, obviously, if you can afford to fly in a very famous person...we probably should have tried that.

So by the time our bill came up, most of the parents had to leave, that could be there. All the lobbyists for the other groups were being paid to be there, so of course they could stay. So when we got up to speak, I think we did a pretty good job, all of us talking, but all the bills that day got passed except ours.

Ours was tabled, and when they table something that means that it doesn't pass but it doesn't go through. Right? It doesn't pass, but it doesn't fail. It just kind of sits there waiting for them to do something with it. And basically, to me, it was their way of saying, "We don't want to look like we don't care about people with disabilities, so we're just going to table it." Instead of just completely shutting it down. And it never did go anywhere further than that. They tabled it and never came back to it. And it was really sad because it was probably the only bill that they saw that day, that could have touched and impacted the lives of thousands of Texas citizens. So that's kind of where we were.

Fields

When was this in relation to the passing of the Americans with Disabilities Act and some other big events like that?

Interviewee

I don't remember [when] the Americans with Disabilities Act came in. What year was that, do you remember?

Fields

Not off the top of my head. [It was passed and signed on July 26, 1990.]

Interviewee

Yeah. I don't either. I don't remember the role that it had played in our bill. Autism was just coming on the radar for...now it's well known but back then, a lot of people weren't aware of what autism was. The diagnosis for my son 1 in 10,000 kids get autism, now it's 1 in 88. So we're doing something that's increasing... (Interviewee's son heard, coming through room and walking up the stairs.) the number of children being diagnosed. But back then, it wasn't...people weren't aware of it.

Fields

After the bill came before the Texas legislature and was tabled, what did your group do? What was your reaction?

Interviewee

We really weren't too terribly surprised. We knew we had a hard battle. We had tried in the past to do something...this was the furthest we'd gone. We felt like we had made enough of an effort that people got to see, and hear the stories and so we did definitely make an impact on some of the politicians.

Before the bill came up, Anne and I would drive down every couple of Sundays, and we would go to every senator's office, and every House of Representative's office and try and get in, or we would make appointments with some, but we would always leave...like, we had cups with autism, you know, the logo: "Help solve the Puzzle." And we would have cookies of things inside, and we would leave those in all the offices. We did that multiple times, just trying to get people to recognize the disability and what impact it had.

Fields

<topic>Impact of the disability rights movement</topic>

From when you were speaking before the Texas legislature, to today, what changes do you think have happened for people with disabilities in Texas and in America?

Interviewee

I think there's much more awareness now than there was back then for all disabilities. There's much more recognition of job availability, workplace...there's a law that allows a company to alter furniture, desks, rooms, entrances...basically whatever the person needs to be able to fulfil their job. I think those things are so beneficial for individuals who have challenges with a regular, "normal work environment," and I think those are probably the biggest things that I've seen. The willingness that people have now to take on a person who has differences in the way they can work or execute their job, other than someone else sitting beside them can do it in a different way. I think that's one of the biggest changes I've seen.

Fields

Have you noticed any changes in attitudes towards individuals with disabilities?

Interviewee

I think it kind of just depends on the culture you're in. I think there's more people who are...less shunned by it. And more people who are open to greeting people...but I think there's always going to be those people who are put off or afraid to approach or speak to people with disabilities because they're uncomfortable with the situation. They don't know how to handle it. For the most part, I think people are becoming much more open and will actually come up and talk to people like my son. Used to be, people would kind of stay away, but now they come up they're most likely to approach him and speak with him. I just think the culture is changing some.

Fields

Since your work in Austin, have you done any further advocacy for people with autism or other disabilities?

Interviewee

I haven't done as much. I will be trying to do...I've submitted to speak at a conference that's coming up next year, on dealing in emergency situations with people with autism, and I'm waiting for that to come through. So I'm doing a little bit, but not the lobbying that I was before. I don't have the support system in place to be able to do that now without my husband.

Fields

Are there any other comments or any topics you'd like to discuss?

Interviewee

There are some people who were much more involved than I was, that I think would be really good, to speak with, that would be Bonnie Lewellen, she's been involved with the Arc of Denton [A non-profit, volunteer organization advocating for people with intellectual and developmental disabilities.] for as long as I can remember. And she's an incredible advocate for...her and her husband. And Tim Cole would be a good person to contact. He's very good. But...it's been an incredible experience to be involved on a political level. To see, just how in depth some of the actual, true, political games can be. It's a real eye opener. But unfortunately, it hurts the people who need their support the most.

Fields

Thank you for sitting down to talk with me today.

Interviewee

You're welcome.