Disability Classics

Editors Note: This section of RDS is intended to highlight "classic" articles or commentary that helped to lay the foundation of disability studies and disability rights, or, as in the case of the article reprinted below, simply make a point that never tires from being repeated! Reprints can be from journals, newsletters or other media. If you have ideas for material that would fit in this section, please contact Associate Editor Megan Conway at mconway@hawaii.edu.

Dee [Lesneski] Says Josie Byzek

Reprinted with permission from Mouth: Voice of the Disability Nation, XI (5) (Jan.-Feb. 2001), 12-13, 44-45. This is a slightly edited version of a January 2001 interview by Josie Byzek with Dee Lesneski, who became known as "the flagpole mom." It begins with an explanatory paragraph, followed by the interview. More about Mouth is at: http://www.mouthmag.com/

Dee Lesneski chained herself to a flagpole in the parking lot of her son's elementary school. The school had refused to provide a sign language interpreter, as ordered by the court, and would not allow her son Max access to his own asthma medication. Due to their denseness at missing his distress and his signed need for his medication, he suffered a life-threatening asthma attack. Outraged, Dee stood her ground at the flagpole for 20 days, until the school backed down and agreed to do as the court had ordered them to do. The police would not arrest her because they viewed the flagpole as US property, not school property. Nonetheless, in vigilante fashion, the "good citizens" of Pennsylvania, USA expressed their displeasure at her daring to stand up for the rights of her son by shooting at her, and trying to gas her in her tent with automobile exhaust fumes.

Josie Byzek (JB): Dee, what made you do it?

Dee: For three years I had battled the school district for what my son needs. And I'd won...We went to due process three times. I've filed numerous state complaints. We went to mediation. Every process we've gone through has said the school district must put someone proficient in sign in class with Max.

Max is in a regular classroom. He has a hearing impairment, and Down Syndrome, and asthma. He knows how to sign. What he needs is someone to communicate with. In the beginning of his schooling, no one signed or interpreted for him when he signed.

At that point, Max's life was in danger. He had no one to communicate with if he needed his asthma medicine. The last hearing was in February, 2000, and the hearing officer said to the school, finally, "I'm a little tired of this. This has got to happen, and I'm giving you thirty days to have it in place." That meant by the end of March. In May, nothing was in place, so I went to federal court. And the federal judge told them that they needed to do everything that had been ordered in February.

Come the first day of school in August this last year, Max had an asthma attack. No one knew what it was. I had gone to the school to check on him. He was blue. He was telling them, in sign, "Call Mommy please!" They said, "He's been doing that all morning. We have no idea what he's saying." No one there knew sign. No one.

I medicated him, he was stabilized, he went back to his classroom. And I was so angry. I didn't know what to do. I had done everything I could. I had gone all the way to federal court, and a federal judge, Judge Cindrich, had told them what they had to do. What could I do that a federal judge can't do? For God's sakes, what could I do?

I said, "This is it. I am not leaving this building until my son has what the court ordered." Well, they got me out of the building. When I got outside, completely frustrated, I realized I could make a stand. I have a ten-year-old who plays baseball, so I carry a lawn chair in the car to watch his games. And Max was learning to jump rope, so I had a rope in the car.

I went up to the flagpole — which is the only thing standing near the school besides a dumpster — and I tied myself to the flagpole.

I said, "I am not leaving here until my son gets the services he needs." That's how it started. I thought I'd be out there three hours, tops.

JB: What did you expect would happen?

In an hour or so, I thought, somebody will be out here saying, "Okay, we'll do what the court ordered."

Well, they didn't. They sent a police officer to arrest me. But they couldn't arrest me, because the flagpole made it my first amendment right. I did not know that.

Thank God I didn't tie myself to the dumpster. They could have arrested me. I would have been trespassing. The flagpole made it freedom of speech.

I wasn't prepared. The flagpole was on blacktop in the middle of a large parking lot. It was hot, 85 degrees that day. No trees, no shade, no nothing. I wound up staying for twenty days and nights. The media showed up almost immediately, and came back every day. The school hated that.

I was shot at from the wooded area by the school. The shot that was fired hit my girlfriend's van. She had brought her daughter, who has spina bifida, and she had to take her girl home. We didn't know if they were going to shoot again or not.

Then a truck tried to run me over, at about three in the morning. It was an older, black truck with Confederate flags in the windows. The form of muscular dystrophy I have is called channel myopathy. When I get cold, I tense up and stay like that. So when it rained or got cold, I got in the tent.

My daughter had come to spend the night with me and it was starting to get cold. The truck couldn't get close enough to the flagpole to run us over, so it backed up and filled the tent with exhaust fumes.

JB: Didn't you call the police?

The police? They did absolutely nothing.

They didn't try to find out who shot at me, or who drove the truck. The security guard the school put there told us, "You're not going to die while the kids are here at school. But when we leave at four o'clock, there will be no protection." They didn't want me dying during school hours, but it was okay afterwards.

There would be school buses pulling up and kids would have flags hanging out the windows with little signs saying, "Justice For Max," "Go Max!" And busloads of kids would be cheering.

And then there would be other buses with kids giving me the finger, saying, "Go home!"

After the school closed at four o'clock, clear through the middle of the night, people would drive by, circling the flagpole, gawking and heckling.

JB: Why did you stay?

Because instead of me being dead in the parking lot it could be my son dead at school from not getting an asthma treatment.

As long as I was in their face, they were cautious about what care my son got.

JB: How did the press treat you?

I did talk-radio shows and a local talk show host told me he would put a drive on to get money if I would consider institutionalizing my child.

I had probably a hundred people say that what I was doing by putting him out into public school was humiliating and degrading to him, that it was a very aggressive idea to bring to a small town. That I actually was sick and "in denial" because I "didn't recognize his needs."

JB: You didn't know about the disability rights movement?

I knew there was a disability movement. I just didn't know there was anybody that would actually work for me right now!

Then my kids started making phone calls, saying, "My mom's tied to the flagpole. She's getting into a lot of trouble. Can you come help?" I have five children. One of my oldest called here [Tri-County Patriots for Independent Living, the CIL in Washington, Pennsylvania]. He talked to John Lorence. John said, "Absolutely. We'll be there."

People from TRIPIL came out and stayed the whole 20 days with me. I was never by myself. I owe these people my soul. They went through everything that I went through. The rain, the cold, the harassment, the sun, not having bathroom facilities, days without eating or drinking.

They fully supported everything I decided to do. The school would come out and say, "We'll put somebody with him. Why don't you go home and rest up?" Well, next week wasn't going to serve the purpose.

I wasn't wanting piloting lessons, I was just wanting what a federal judge said was necessary for my son.

JB: Where do you see yourself and Max in our history?

I'm not comparing myself on any level to Rosa Parks, but when she got on the bus, she wasn't leaving the front seat. I wasn't leaving that flagpole until the school did what a federal judge ordered for my son's education.

It is a damn shame that a little boy who wouldn't say a bad thing (loving someone to death would be the biggest harm he could do) that there would be a protest about him being in a public school!

I was asked by a number of interviewers, what could be gained by what I did. The only thing I know is that kids are kids. It's what we teach the children that makes a difference.

Max does have a signing aide with him at all times now. He's in second grade, with the other

second graders, doing regular science and health. He gets help with reading and math. But other than that, he's doing the same curriculum as the other second graders.

It's harder for him. I spend three hours a night working with him because they don't modify the communication on his subjects to allow for his hearing loss. It's like all they can see is the Down Syndrome.

I still get mail saying to remove him from school. The school district made me explain why I wanted him in public school, to parents who wanted to sue me to have Max removed. All they kept saying was, "That animal needs to go home."

And I still cannot go to open house like any other parent. His Christmas program is next Monday. I will be heckled the whole time.

It's still there. Standing in line at the grocery, people will leave the line when I have Max with me so they don't have to look at him. Being the last one into the doctor's office but the first one called. It's there.

JB: You work at TRIPIL now. What are you learning?

You know how when you wake up in the spring, you can just smell that spring is here? You can smell the rain? It's like all of a sudden, I realize what it's about. My eyes are opened.

I had no idea I was going through life with my eyes closed.

Correspondence

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