

# Matthew, In His Own Words | CPD Blog

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04/30/2019

## On Life With A Significant Disability, Getting An Education, & Teaching Others

Matthew Wangeman came to the Center for Persons with Disabilities on Friday and fielded questions in a private interview, with CPD staff members, and at the showing of the film, *My Dad Matthew*, at Utah State University. Here's what he had to say on several topics through his re-voicer, Kelly Hurlbut, who watched as he used a pointer on his helmet to indicate letters and words on a board in front of him. (Sometimes Kelly took over telling the stories she knew well. The parts that are not direct quotes from Matthew are in brackets.)

This article combines information from the three Q & A sessions.

### On Having A Movie Made About Him

It's very interesting because when John Schaffer, the director, came to me with this idea, it was not going to be called *My Dad Matthew*. My son happened to be there the first time filming, and he stole the show.

I have had people ask me, why didn't I put in the hard parts of my life? First off, it's just six minutes. [He laughs here, and it's infectious.] And to me, my life is not hard. It is just who I am. I have gotten to go to [University of California] Berkeley, I had a family, I'm a professor at Northern Arizona University. I'm just like anybody else."

### On His School Days

When I was born, the cord was wrapped around my neck so I could not breathe, and the lack of oxygen caused cerebral palsy. When I was two, my father passed away. He was a test pilot for Grumman on Long Island, and on his birthday there was an issue with the plane and he crashed and died. So my mother was at home with two kids, one with a significant disability, so in 1967 I went to a school for crippled children in New Jersey.

I stayed at that school for 13 years. When I was 12 I had this scary thought that I could be there for the rest of my life. Sadly, I know people who are still there. It was not a bad school, just no opportunities. [That school is] more like a hospital now.

Luckily some of the other students were transferring to a school in North Dakota that was giving diplomas. I wanted one, too. So I froze my butt off for four years. [I transferred when I was 15 because my first school kept saying] they would try to get me into a local school in New Jersey. But they weren't getting anywhere.

I graduated valedictorian out of a class of 6.

### On Going To Berkeley

I knew I needed to go to college if I wanted to and make something of myself. And there was this student who was two years ahead of me. She was going to this university called Berkeley. I had no idea what Berkeley was, but if she went there, I could go there. So I had a friend from my first school who was living in Berkeley, so I asked him to get some information.

When I told my mom I wanted to go to college, she laughed and said, "How can you?" To me, I knew I had a good mind, so why not? [She had him tour group homes first, which only solidified his plan.]

Berkeley had a program for people with significant disabilities in order to help them go to school, so when I visited Berkeley I met with the director of the disability student program. And I guess I really impressed her, because after the interview she said, "See you next year." [Berkeley was where the first student with significant disabilities, Ed Roberts, received his higher education. There is nowhere else that offers a program for students with significant disabilities, and it has since been discontinued at Berkeley.]

When I went to Berkeley, they had one person who was there 24/7 just in case. They had a pool of people who they screened who wanted jobs to help people with disabilities. In fact I met one of my best friends there. We are still good friends. In fact, he actually did his dissertation on me, about disability and sex, because we would talk about girls. We were in college. What do you expect?

I could tell you stories, but I won't.

Berkeley was hard. In my two schools I was the best student. When I went to Berkeley, I was not the best student. But I would say the education that I got there was not in the classroom. It was in the community of people with disabilities. They really taught me it was my responsibility to help change the world for people with significant disabilities.

So that is how I got started in all this.

## **On His Communication System**

[Matthew has an iPad. He uses it when he wants some time to himself, "kicks Kelly from the house," and then texts when he would like her to come back. She has lived in and provided communication services for him for the last 5 years. He has found the communication board and re-voicer system he uses to be the most reliable for him. It doesn't break down or fall down.]

## **On Teaching At Northern Arizona University**

About ten years ago, Kathy, who is my co-teacher, and I developed the disability studies minor for NAU. Kathy is a speech pathologist. She came from the medical side of things. I am an advocate. In April Kathy and I presented at the speech conference in Phoenix. We talked about how speech needs to take a more disability studies approach."

[One of Matthew's favorite jokes:] I had speech therapy for 10 years. Look at me talk!

I love teaching because I know my students really think about disability differently after taking my class, and to me our work at University Centers of Excellence on Developmental Disabilities is all about changing perspectives.

I am not saying research or policy is not important, but you need to change how people think about disability. We can make laws, and we have, and we have made a lot of them. But until we change how people view disability, we are just spinning our wheels.

I think disability studies is part of diversity, just like women's studies or indigenous studies. Most people don't recognize it like that.

We can learn from people who have been oppressed. It is weird because when I say people with disabilities have been oppressed, my students look at me weirdly because they never thought of it that way. Today, to me, people with significant disabilities are still being oppressed. They cannot get jobs that pay well. They cannot live where they want.

I think for me, everyone thinks I have made it. But I make 13 grand a year. In order for me to keep my SSDI I can't make any more money. [His salary would have to leap to 70,000 per year to cover the cost of caregivers and pay his benefits.] There's no stepping stone for people with disabilities. It is all or nothing.

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## **The Future For Students With Significant Disabilities**

That is very hard, because most people with disabilities don't have many friends. And we don't create a social network for them. In high school many students with significant disabilities are just left to fend for themselves. So they feel very alone, especially after high school. That's when they usually end up in sheltered workshops, group homes. I think we need to start over.

[The world is not more prepared for student with significant disabilities now than it was when I was a student.] Especially not in higher education.

Special education should not exist. In my opinion, especially for students with significant disabilities, it has hurt them. A student with a significant disability may need extra help. That is OK. But don't separate students.

If we had a five-year plan to really change the system, I think we could.

## **On Advocacy**

In Arizona I am a "smart mouth." I have had my life threatened for standing up for people with disabilities. It is very sad. I think people just don't want to change.

[Matthew urged his listeners to join the [Teaching Disability Studies Facebook Group](#).]

## **Advice For Students With Severe Disabilities**

[Matthew credits his own success to his stubbornness. If he had not advocated for himself he might still be in the school for crippled children that he attended in New Jersey. Not everyone is born as hard-headed as he is, but they can acquire the skill.] Parents need to teach it. Many parents want to protect their children.