

## ***Disability Stories Interview with Cyndy***

**Cyndy:** This is Cyndy. I live in Spokane, Washington. You could probably say that access to health insurance and health care and making sure I don't lose it has probably the biggest struggle I've had as an adult. When I was in my mid-20s, I was diagnosed with crohn's disease. That's an autoimmune disease. It affects your intestines. I have a ... it comes in a few different varieties: mild, moderate, severe and then some other category that's like very much worse than severe. I have the very-much-worse-than-severe category, where you're not supposed to go wandering around in the Alaskan Bush for days or put yourself in other situations where you can't have medical care. A lot of my adult life has been shaped by need for access to health insurance, health care, and just making sure that I didn't do anything to lose coverage, like where I've worked and where I've lived. For few years I was on – in the mid-2000s, I was on a medication that wasn't too expensive, a bunch of pills. In the late 2000s, I was moved to an IV biologic drug that I received at the local hospital in my small town my small city – in Arizona at a cost of \$18,000 to \$29,000 a dose every 8 weeks (clarification: A majority of these costs were paid by insurance). So I was one of those patients that had costs so extreme that even when I was healthy I would eventually hit that million-dollar lifetime maximum. My costs kept rising. While I worked, I still had out-of-pocket maximums that I met every year and eventually those got bigger and bigger. So I stopped doing things like flying home for Christmas to see my nieces. I was single. I didn't have a family. I didn't have any relatives where I lived. I didn't go shopping very much. I didn't really do fun things. I didn't leave town. Eventually it became hard to even do things like leave home to go hiking in the Grand Canyon: The permits and the gas were a big consideration. At the same time, I was stuck in my job. I was a newspaper reporter and newspapers, you may know, are not doing that great. So I was on this sinking ship but there was sort of no other place to swim to. Other jobs that I looked at had exclusions on when they would cover medical problems. You'd have to go 2 or 3 months before coverage would start. And when you're paying

\$18,000 or \$28,000 a dose for medicine, it's pretty hard to do. I was scared. A lot. There were these lifetime limits on coverage. I knew that I couldn't buy coverage. I was scared of losing my job, which was inevitably going to happen to everybody in our newspaper at some point. I couldn't qualify for Medicare without becoming seriously disabled and meeting criteria that I hope to never meet and waiting two years for health insurance coverage. And at that time in Arizona, Medicaid coverage was only available to people who were earning less than \$500 a month, which was not anything I ever wanted to do. So my goals were mostly to have a life, a work, not be totally sick and to have a personal life. At the same time, I was a news reporter, so I was interviewing other people who had cancer, who were scared to leave their jobs, who were scared their kids could lose insurance. I even know one person who had married somebody who was just kind of a friend because she needed insurance. So every fall when the insurance choices were released at work, I'd run to my computer and run the numbers on what it was going to look like for the coming year and what our options were. And then my coworkers would come over and we'd look at: "What if your kid lands in the hospital again this year? What if you're all healthy all year? What if two of you get really sick?" And we'd do this every year. And my coworker said "You know, you really like doing *this*." I'd been looking around for a new career, but I didn't know what to do. I was seriously stuck. I was in a career that wasn't going anywhere. And I was scared to leave. Even though I really loved my career, I had to make other plans and I didn't know how. So this career idea struck me that I can eventually help people somehow in healthcare. Then the Affordable Care Act started to emerge, take shape. The idea that insurance companies – big, awful, terrible insurance companies – would have to sell insurance to people like *me* was pretty appealing. The idea that people who had really high-cost diseases and medications, that they wouldn't hit these lifetime limits, that was pretty good too. But I started making other plans also: Well, what if the ACA didn't work out? I could join the high risk pool and move to Washington State. That would cost about \$11,000 a year if I was healthy. I could stop working in order to qualify for Medicaid. I could marry a Canadian – any Canadian, anywhere in Canada, preferably a lonely Canadian – who really needed a wife. (laugh) These were actual thoughts

and plans that I had while I was working a second job that I eventually needed to take up on nights and weekends to be able to cover health care. So then the Affordable Care Act passed, which was shocking. I got up extra early that morning so that I could be done crying before I needed to go out and interview people as a reporter. And then I cried hysterically when I found out that it was upheld (at the Supreme Court), which was a shock to me and my co-workers who had cancer, alcoholism, serious mental illness and a variety of other disabilities. So I changed jobs. I went to grad school. I changed careers. I purchased COBRA for half a year. And I kept my wages low enough that I could (later) have Medicaid. Now I work for one of those big huge insurance plans. I actually wouldn't say that the place I work is awful or evil and it's a nonprofit. I work every day trying to help people. My drugs are \$3,000 to \$5,000 a dose that the insurance company pays for. I have great insurance through my work and I talk to people every day who are struggling with costs on the state marketplace. I also have a life. I don't work two jobs to pay for healthcare anymore. I have been able to date, get married, have a family thanks – largely to the ACA.

**Interviewer:** (Question inaudible).

**Cyndy:** I've never wanted to need to prove that things are severe enough that I can't work for 2 years. [Clarification: two years of being unable to work due to disability is a requirement to establish disability if seeking federal disability determination and Medicare.] I always hope that doesn't become the case. But I did formerly, very recently, work with people for two years for whom that was the case. And we talked often, every day, about their options for health insurance and maintaining health insurance. And buying Medicaid came up. And those topics and how to maintain Insurance were both key for them and one of my favorite parts of working with people on disability benefits, because that was usually the first question after: "What happens to my (Social Security) check?"

**Interviewer:** (Question inaudible.)

**Cyndy:** Yeah, I hope to stay healthy and working. I do often think through other scenarios if my condition worsens. For example, I would not take on debt that you wouldn't be able to discharge if found disabled. I wouldn't privately refinance student loans, for example. But other than that I don't really have a big safety net in place if I were to become disabled. It's just mostly I'm hoping not to be more chronically ill.

**Interviewer:** (Question inaudible.)

**Cyndy:** I get my health insurance through my employer – that large nonprofit health insurance plan that I work for. Coverage through my spouse's employer would cost more than half of my pay. Coverage on the on the state health exchange, um, would cost about a quarter of my paycheck every month, but that is our most most likely next bet. Part of the reason that I work where I work is because I have phenomenal insurance benefits. In fact, I even take took a pay cut realizing that the costs I won't pay in insurance will more than make up for it. But that is still a strong factor in me deciding where I work and one that's not easy to compare. The place where I last worked eventually again started decreasing how much health care it would fund and our deductibles and our out-of-pocket maxs kept increasing. And that's something that's hard to shop around on when you're applying for jobs.

**Interviewer:** It's not something a lot of hiring managers know about.

**Cyndy:** (Laugh). You're like, come on: this is like not knowing what your pay range is per hour. Like, this is one of the basics.

**Interviewer:** So if they repeal the ACA, how would it affect your life?

**Cyndy:** Just me, or me and other people I work with? Probably just me.

**Interviewer:** Yeah, start with just you.

**Cyndy:** As I view it, the ACA is partially repealed. The mandate that we have insurance, the tools that keep the pool semi-healthy are removed so

the ACA exists only partially. So if it were removed entirely we'd be back to what I'd call the bad old days where you're trying to marry someone who has insurance or trying to be poor enough to get Medicaid or, um, just trying to find some income limit to stay over and under or some system to join where you could get insurance, we would be back to that for me.

**Interviewer:** I think about that sometimes as a feminist issue, like women getting married for health insurance and staying married because they need health insurance (becomes inaudible).

**Cyndy:** Well: Babies. Men don't have a lot of those, so... And that was not previously covered right, before ACA.

**Interviewer:** So does your insurance that you have right now let you get the health care you need?

**Cyndy:** I haven't experimented with it very much. I am in an HMO kind of a plan and so far it's been easier than I expected to get the prescription IV medication that I take, find doctors I need, and have the doctors that I've grown used to seeing be in my network. It's been OK. The bigger difficulty has been getting time off work to get there. But it's gone pretty well. But I was really apprehensive because in making a career change I wasn't just talking about health insurance. Well, I wasn't just talking about a paycheck. I was talking about what drugs were covered with a woman who was interviewing me for a job, which was extremely uncomfortable.

**Interviewer:** Yeah, that makes you stand out in a way that is not how you want to stand out.

**Cyndy:** But I had to go there 'cuz it was the only insurance.

**Interviewer:** You've got to. It's just one more of those barriers. So, does the cost of your healthcare cause you stress?

**Cyndy:** The cost of my healthcare used to be the number one overriding dark scary cloud in my mind all the time, every day in the past. Before the

ACA. It was that thing that's just in the back of your mind all the time. Now I know I'm covered. Things are good. I have great coverage. But the options for coverage under things like the (state) marketplace are sort of receding and I don't hope to be poor enough to be eligible for Medicaid again. So knowing, knowing the general direction of what's happening, I don't feel extremely protected in the case that I were to change jobs.

**Interviewer:** Yeah even if you can open that door to Medicaid, there's a lot of other doors that you close and when you suppress your earnings.

**Cyndy:** Yeah, you need to suppress your earnings.