

ASED Presentation
September 25, 2008
5:30 p.m.

Good evening. Thanks so much for inviting me here tonight. My name is Candice Lee; I'm the Project Coordinator for a new initiative at the Michigan Department of Community Health – Health Promotion for People With Disabilities. First, I'll tell you a little about me, and then I'll tell you a lot about the program I work for.

My story parallels a lot of stories in this room. I was born with a rare spinal condition called sacral agenesis; that means that the vertebrae that make up the sacral region of my spine are missing. Shortly after my birth a fancy team of specialists presented my mother with extensive lists of things I would never do. They stopped short of recommending she put me in a home and lose the key...but not by much. Fortunately for me, my mother discovered and implemented a rare and radical form of therapy that saved my life...it's something you might have heard of... she told the doctors they were full of crap. She took me home. And she had expectations.

Because of these expectations, I became the first person in my family to graduate from college. I started my career in education – both ends, first working for the Head Start preschool program and then for Central Michigan University. It was while I was at Central that I had my first experience working within the disability community; I hired on as the Family Support Coordinator for a program called DB Central, a services program for children who are both deaf and blind. It was some of the most meaningful work I'd done. I helped parents navigate the maze of insurance, disability benefits, section 504; planned weekend retreats for families, introduced some children to the joys of skiing. I found that my own experiences gave me a measure of credibility with the parents; we had traveled some of the same roads. I was hooked. After leaving DB Central I went to work for Michigan Rehabilitation Services, the state's VR agency, for a pilot program working directly with employers.

Just as that program was ending, I met Judi Lyles in the Michigan Department of Community Health. Dr. Lyles had applied to the Centers for Disease Control and won for Michigan a competitive federal grant designed to integrate people with disabilities into existing public health programs. They were looking for someone to coordinate the program, and I jumped at the chance to interview and got the job in February.

Here's where I stop talking about me and get on with more interesting things. This program originated when the Centers for Disease Control and Prevention – the CDC - identified a disparity, an enormous gap, between the health status of people with disabilities, and people without – we'll talk more specifically about that in a minute – and the surgeon general's public health plan for the nation, Healthy People 2010, added goals aimed at closing that gap.

Michigan is one of only sixteen states with such a program, and we're one of only a small handful that has the program located within the state's public health entity. In most other states this program is located at a disability resource center within a university. As they say on Seinfeld, not that there's anything wrong with that. But I think it says a great deal about MDCH, that they wanted this program. Having this program at the Michigan Department of Community Health tells me that MDCH is concerned with the health of

ALL the state's citizens, that this isn't viewed as an academic problem, or something for the disability community to address alone – it's a public health issue.

WHERE we're located within MDCH also spoke to me. Health Promotion for People with Disabilities is in the Chronic Disease and Injury Control section. We're not housed with Medicaid or Children's Special Health Care or some isolated niche carved out solely for people with disabilities. We're with tobacco cessation and diabetes management and injury prevention...in a place that's focused on health, not on disease, the intersection where public health can change lives.

Michigan was awarded the grant for five years; the first year ends on September 30. Primarily, it's for capacity-building. That means carving out space in the department, hiring staff (that's me) and getting commitments that support the program in ways like clerical support, epidemiology, evaluation. It also means building a coalition comprised both of public health and the disability community and doing the strategic planning that will drive our activities for the remaining four years.

In addition to capacity-building, the CDC funds in what they call modules – money for specific activities. The only module funding we received is for what's called, in the public health world, surveillance. It doesn't mean we're tapping your phone. It means that when public health information is gathered in Michigan, it's now going to include information specifically about people with disabilities. Every year the state conducts the Behavioral Risk Factor Survey, or BRFSS, a random phone survey on the health status and behavior of its residents. Our module funding is paying to have additional questions on people with disabilities added to the BRFSS – the clearer we are on what the issues are, the better we can address them.

The data we have right now is sparse...and it's grim. 40.7% of people with disabilities say their health is fair or poor. Only 7.3% of people without disabilities say the same. People with disabilities are at greatly increased risk of secondary conditions, like depression, obesity, diabetes and osteoporosis, that have a big impact on our quality of life.

The data don't speak to the reasons for this. But some of the reasons are fairly self-evident to people in the disability community. Number one is access to healthcare and preventive care. If I can't get transportation to the doctor, can't get in the door, onto the exam table, onto the scale, up to the mammogram machine...if my doctor only sees my disability...if he doesn't see me as a whole person, who gets colds and has sex and needs contraception and has children and gets older, in short, who needs the entire continuum of care his other patients need...then it's no wonder.

But is some of it internal? Are we guilty of the same thing the doctors are – seeing our disability at one end of a continuum, and good health at the other? The World Health Organization is developing what they call the international classification of functioning, disability, and health, or ICF. Instead of the old medical model, where disability is viewed as something that's wrong, and that something wrong is in you, they're working to classify disability as what happens when your body meets the environment. Here's a quote from the WHO:

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some

degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience.

This is good stuff. But what do we DO to further that concept, and to close that health gap? What is the Health Promotion for People with Disabilities initiative DOING? What can we DO as individuals?

Here's what we've been doing: Health Promotion for People with Disabilities will be wrapping up our strategic planning on September 30. We've put together an advisory council comprised of both public health and disability-related organizations, and we brought them together for the first time in March to learn a little about each other. It was important for the folks from the disability community to learn about the public health approach; we're fortunate to have strong, seasoned advocates and service providers, but they're used to working with individuals, counting their progress one person or one fight at a time. Public health works with populations; if a health-related issue affects an entire POPULATION – women under 30, African-Americans, people with diabetes – then it's a public health issue. People with disabilities are a population public health is just starting to look at, and it's not easy, because we are so diverse. Public health, on the other hand, needed to have an understanding of what the issues are in the disability community right now. They needed to know why some of us are so darn mad. And trust me, now, they know! ☺

Over the summer we've broken out into four different workgroups according to the four dimensions of the Surgeon General's *Call to Action to Improve the Health of People with Disabilities*:

- Increase the understanding that people with disabilities can live healthy, productive lives
- Provide health professionals with the tools to screen, diagnose and treat the entire person
- Increase awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle
- Increase access to healthcare and promote independence

Each workgroup is about half and half, public health and disability community. And I as I said earlier, our only funding is for surveillance, so we don't have pots of money to distribute for these workgroups' activities – it comes down to, what can we do with our pooled time and resources?

And what the groups are doing already, really is remarkable with such limited resources. The Access group has obtained a curriculum from the state of California, aimed at educating health providers on the basics of access for people with disabilities. They're working with the Health Professionals group to generate a speakers' bureau of people willing to deliver this training to health professionals. We're identifying organizations of health professionals and trying to make inroads in their professional conferences; doctors are part of the picture, but we also want to get to nurses, office staff, all kinds of allied health workers, because they often have more to do with our experience at the clinic or the hospital than a physician does.

The integration group is working with every chronic disease prevention section at MDCH, reviewing their strategic plans and work plans for inclusion. The 'Living Well with a Disability' workgroup is supporting the introduction of the Stanford Chronic Disease Self-Management program, a six-week course centered on living well with any kind of chronic condition, into centers for independent living across the state, starting with a pilot at CACIL here in Lansing. In fact, I've just become a master trainer for this program, and expect to be the one leading the course at CACIL. If you're interested, talk to me afterward.

While all this is going on, I've been working internally at MDCH, meeting with each chronic disease prevention section to unearth the ways in which what we do overlaps, providing them with ways to make what they do more inclusive wherever we can. I've really been struck by the level of engagement people have for this program. They're interested, enthusiastic, curious. It leaves me very hopeful about our chances for success.

And now, about us. What can we do as individuals?

What we can do, are many of the things you've already learned from long experience; the same things most everyone should do to manage their health become even more important for people with disabilities. Keeping a personal health record. Making time for your yearly physical – not only is it good for you, it's another reminder to your doctor that your health does not begin and end with your disability. Ask questions, make lists, do your research. Don't be afraid to interview – or to fire – your doctor. Whenever I see a new doctor, I dress like I'm going to a job interview – and I insist on talking with him clothed first, it's important that physicians see us as whole, competent beings. My primary care doc also sees my husband and daughter; in these ways, I'm bringing my outside life with me into my relationship with my doc.

And, it might not be fair, but, yes, we have to take it upon ourselves to educate our healthcare providers when the need arises. Not about the whole world, always, but about what YOU need in order to access the full spectrum of health care, so that you can achieve and maintain what optimum health is for you. Maybe if enough of us do just that, even healthcare providers will recognize disability as part of the universal human experience.

Thanks for having me here tonight.