

Fontbonne University Commencement Address
December 17, 2011

Thank you very much, Mr. McGlynn.

Dr. Golden, Mrs. Golden, members of the Board of Directors, Faculty, Staff, graduates and families, my family and friends, Good morning. It's my honor to be here today. Thank you for your warm welcome.

To the graduates-Congratulations! You've worked hard and given it your "all" to get you to this day. I wish you the very best and brightest future. Enjoy today. Tomorrow is just on the horizon and that's when you really have to concentrate on how you will best use the knowledge you've gained, and the gifts and talents you possess, in a way that maximizes your potential.

'As Dr. Golden said, the Fontbonne mission challenges you to "think critically, act ethically and to assume responsibility as citizens and leaders long after graduation." I've come here today to challenge you to live that mission by becoming agents for change.

What do I want you to change? Societal attitude toward disability. Your attitude toward an issue drives how you will approach it. But first, you must look within yourselves and think about your own perception of disability; it's a normal function of life and what matters most is that we are all people first and a disability doesn't define who we are, it's our character, integrity and humanity that does. If we can all approach disability in a positive way, the world will become more welcoming toward people with disability.

Initially, both my husband, Max Starkloff, and myself were invited to address you. I've brought his words and his spirit with me today. So indeed both Max and I are here on this podium before you.

I am proud that Fontbonne chose to dedicate the Fall Semester, 2011 to the study and awareness of Disability. It surely exemplifies your mission. The inspiration for this came from Dr. Margaret Gray and Dr. Susan Lenihan. They wanted to celebrate the Americans with Disabilities Act of 1990. I thank them, Dr. Golden and faculty members, for their support. The ADA is the most profoundly important civil rights legislation for people with disabilities in this country's history yet we have so far to go to even the playing field with the rest of the general population. I hope the students who participated in the events that were put together this past semester, experienced profound learning, enabling you to become an agent for change in the world. Before you can change something, you have to first understand it.

I don't say that lightly—become an agent for change in the world. I learned to become an agent for change through my husband. He had been in a car accident in 1959 and was quadriplegic due to a spinal cord injury. He used a manual wheelchair that he could barely push himself. He lived at home for 4 years and went through many attendants, who helped him get bathed, dressed and out of bed. But they were unreliable and expensive. He ended up in a nursing home because in the early 60's, ongoing attendant support was not available as a community option to the general public and primarily only to the wealthy. He was 26 years old when he entered that institution and the average age of the people who lived there was 80 years old. If he didn't do something dramatic, he was afraid he would die there. The attitude back then was that someone had to "take care of" disabled people. But he wanted to take care of himself.

So Max, never a quitter, began to plot his escape. He thought that housing and attendants were critical issues to start working on. He also realized that he wasn't the only person who needed this. He began meeting other disabled people and organizing a grassroots effort in St. Louis to change public attitudes toward the disabled, and public access for people with disabilities. It wasn't easy. In the late 60's Max got a power wheelchair. He was elated. While most people saw wheelchairs as symbols of tragedy, he saw his new chair as liberating! He could wheel around independently. But public buildings had steps, you couldn't get up curbs, you could not ride a bus or train and housing was not accessible to people with disabilities. He founded Paraquad in 1970 to begin working on eliminating these barriers and improving public attitude.

He also traveled to Berkeley, CA where he met a motley crew of disabled advocates, led by Ed Roberts, John Hessler and Hale Zukas. Ed had polio, slept in an iron lung at night and had a ventilator mounted on his power wheelchair during the day. John had a spinal cord injury, was quadriplegic, and used a power wheelchair. Hale had cerebral palsy and used a communication device that he typed on with a stick mounted to a helmet he wore every day. These men, and others with significant disabilities, like Max, had started out living in an institution--on the campus of the University of California, Berkeley. They, too, were tired of having other people decide who, and how, and at what time they would get out of bed every day. They banded together, pooled their benefits checks and began to hire students to be their attendants and assist them with the most personal of needs so that they could actively participate in campus life. This was the first time for most of them that they had control over their bodies and their lives. They created a disabled students program on campus and went from hiring attendants to installing ramps, curb cuts, and making classrooms accessible to all students. When they graduated, they used their campus advocacy success to create the first Independent Living Center in the world. From that Center they could pursue the same types of changes they had made on campus, in the city of Berkeley. Equality, independence, accessibility and attitudinal change were the goals. Their ideas caught on like wild fire and within a few short years, independent living centers were cropping up all over the United States. The Disability Rights Movement was born!

Max was energized to hear their story and have new friends whom he could work and strategize with. He returned to St. Louis empowered to continue his efforts to change the world. And that's how it works. One person meets another person. They talk about issues they both care about and the next thing you know, they're creating a revolution!

I came along in 1973. I took a job as the physical therapist at the nursing home where Max lived. I was fascinated by this handsome, intelligent visionary who told me that people with significant disabilities shouldn't have to live in nursing homes simply because they can't get out of bed by themselves. He told me he could be in charge of his own life and make his own decisions about how he would live, and that other people with disabilities could do the same. His personality was electric-his vision revolutionary. I fell in love. I decided that there were plenty of physical therapists in the world but not enough agents for change.

I not only joined up—I married him! Lucky me! We were a team and we learned from our experiences and from other people with disabilities about what needed to be changed.

When we started out Paraquad was a Mom and Pop organization—Max and me.

It was the mid-sixties. People were advocating for the rights of women and African Americans. We were in an unpopular war in Vietnam and people were questioning authority. It was a perfect time for people with disabilities to question authority over them. Disabled people began to believe that they could control their own lives.

We worked on curb ramps in the city and county of St. Louis and lifts on buses. We were told that these were costly and useless ideas. “After all”, people said, “you never see people in wheelchairs out on the street”. If the expression “No, duh” had been coined by then, that’s what we would have said. Of course you didn’t see them. You couldn’t even get off a curb without crossing at alleys and wheeling in the street. It was demonstrative of societal attitude about disability. Out of sight—out of mind.

There were other issues, too: access to housing, education, transportation, sign language interpreters, Braille, attendants, deinstitutionalization for people with mental illness and employment. These issues were the same in Berkeley, Minneapolis, Denver, Washington, D.C., New York, Chicago and Boston. And also in small town America. We met people all over the United States, and then the world, who had the same aspirations that we did. People like Judy Heumann, Ed Roberts, Justin and Yoshiko Dart, Marca Bristo, Charlie Carr, Shoji and Yuki Nakanishi and so many more became our mentors. There was strength in numbers and our collective power was growing.

Advocates won most of those battles, many of them because of the ADA. With each success, we were empowered to keep going. We didn’t win them all, but we never gave up.

Max was a self-described “average Joe” who became a national and international leader. He was sought for his opinions and advice by local, state and national politicians, as well as his disabled colleagues. The news media was at our door

when some hot disability issue came up. An Emmy Award winning documentary was made about his views and he instigated the exhibit “The Americans With Disabilities Act—Twenty Years Later” that is currently on display at the Missouri History Museum. Max was an agent for change.

If you asked Max and me 40 years ago what was the single greatest barrier facing people with disabilities, our answer was attitude toward disability. But 33 years later societal attitude toward disability was still the biggest barrier, despite all the gains advocates had made. We left Paraquad in 2003 and started the Starkloff Disability Institute to focus even harder on improving attitudes toward disability.

Max Starkloff was a visionary who saw a need to change attitudes at two levels. Here’s what he said:

We must “influence how society perceives disability, and how people with disabilities perceive themselves. In order for the Disability Rights Movement to achieve true long-term success, it is essential that these critical issues be addressed.

If asked to prioritize the two issues, I believe we must focus first on the self-perceptions of people with disabilities. We need to develop a very aggressive plan to get disabled people involved proactively in matters which determine their lifestyles and influence the overall quality of their existence. This doesn’t necessarily mean that each disabled citizen must become a political or social activist – it does mean, however, that they have to take a more considered look at matters which determine the course of their lives. They need to study and understand the positions of political candidates of all parties, be aware of key public policy initiatives at all levels, and speak out when discrimination toward any person with a disability occurs in our society. *In other words, people with disabilities must be able to exercise their basic rights of citizenship.* The more our voices are heard, the greater our chances of educating the public and policy makers about critical disability issues.”

“American society, for the most part, still does not view disability in the context of civil rights. Instead, many continue to believe that if everyone just understood what the problems are, they would be compelled to “do the right thing”. Stated a bit differently, those who subscribe to such a view likely would wonder how

anyone could be other than supportive of a person with a disability. I see that as paternalistic. Having lived with a disability for more than (50) years, I'm convinced that while well intentioned, most people have such a fear of disability that they simply cannot get beyond what amounts to a patronizing attitude. It's a means of self-protection from something not understood. True understanding comes from the knowledge that all people with disabilities deserve equal opportunities to share in the same amenities our communities have to offer. Nothing more and nothing less."

He goes on to say that, "One out of every five people in this country has a disability, and the massive economic and political power of this minority group remains largely untapped. Simply stated, it is imperative that people with disabilities be educated about their rights and their strength."

Another way to change societal attitudes is to get disabled people into the workforce. Max saw employment as the "Next Big Step" toward full equality. Having a job defines how we view ourselves. Now that you've graduated, you plan to get a job and move on toward your dream of success. Millions of people with disability cannot count on that happening. Without a job, they are doomed to live a life of poverty. Currently, while one third of non-disabled Americans are out of work, two thirds of disabled Americans are not working. Unemployment is the unfulfilled promise of the Americans with Disabilities Act. People with disabilities are the largest and poorest minority in this country.

Now what does all this have to do with you? We need you. This Movement has stood and grown on the relationships of all types of people and groups who've come together to support it. And it's growing around the world. In June, 2011 the World Bank and the World Health Organization released "The World Report on Disability." In it they estimated that 15% of the world's population has a disability. That's one billion people! We all *have to care* about the issue of disability and take a positive approach to creating a world that welcomes all disabled people.

What can you do?

Be an agent for change every day! If you are an educator, include children with disabilities in your classroom. Take a stand on bullying and teach children

acceptance. If you are an employer, promote hiring people with all types of disabilities and make sure they have a chance to move up the corporate ladder, just like you want to do. If you have a child with a disability, believe in her independence. If your work involves assisting disabled people to change their lives, recommend community options first and assist the disabled person to make their own decisions. If you get involved in political campaigns, find out what the candidates' stand on disability is and educate them if they don't have a stance. Get to know your neighbor or co-worker who has a disability. Talk to them about what you'd talk about with anyone else you meet for the first time: St. Louis as the World Series Champs; Pujols leaving St. Louis; the Ram's lousy season; the weather; or some hot news item. Ask them about how best to include people who have a disability. Don't turn away.

Believe it or not, change often begins with one person. You can be that one person and change attitudes about disability. You can "think critically, act ethically and ... assume responsibility as citizens and leaders..." We did, and we raised three wonderful children, too. You, too, can be a revolutionary.

I want to ask you now if you will make a pledge. The only answer to this pledge is "I will". If you can answer affirmatively, I want to hear your answers, so please shout them out.

Will you treat people with disabilities as you want to be treated yourself? "I Will"

Will you take a stand in support of people with disabilities living full, integrated lives in the community, just like yourself? "I Will"

Will you promote hiring people with disabilities and welcome disabled co-workers? "I Will"

Will you ask political candidates to stand in support of policies that improve lives for all people with disabilities? "I Will"

Will you be an agent for change in the world? "I Will"

I'm counting on you. God bless you with great success.

Thank you!

Colleen Kelly Starkloff, Co-Director The Starkloff Disability Institute