

Systemic change doesn't always filter down to real change in the personal lives of people with disabilities, so we need

Change. We all want it—and we want it now! We want children and adults with disabilities to have better lives. Because many of us believe that improvements in the system will result in a better quality of life for individuals with disabilities, our advocacy is

directed toward legislation, increased funding, more programs and services, and so forth. There's something wrong with this picture, however.

The United States already has more laws, programs, and services than any other nation. Billions of dollars are spent on federal and state programs and services. Even so, the unemployment rate for people with disabilities has remained at 70-75 percent for many, many years. Students with disabilities are still excluded in schools. And community inclusion and living real lives remain unfulfilled promises for most children and adults with disabilities. So while changes in public policy are important, changes in the system *cannot* guarantee the precious elements of life most needed by individuals with disabilities: inclusion, participation, friendships, and living natural lives as citizens in their communities.

I believe the best way to effect long-lasting change in order to achieve our goals is through positive, enthusiastic, creative leadership in our communities. Many may dispute this notion as “pie in the sky” thinking, and I understand the criticism. I, too, once believed that systemic change would provide all the answers. But I have found (as have millions of others) that systemic change doesn't always filter down to *real change* in the personal lives of people with disabilities.

I don't need research to prove this point; you probably can describe your own experiences that illustrate this fact. The unemployment rate and the high number of children still excluded from regular ed classrooms, despite laws and programs to address

Community Leadership for INCLUSION

Revolutionary Common Sense
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these issues, provide stark testimony about millions of others.

In this nation of plenty—plenty of laws, programs, and services—why is inclusion so hard to find? Because, like love, we're looking for it in all the wrong places!

We look to the system instead of where inclusion actually takes place: *in the community!*

When we change the hearts and minds of people in the community, we'll see real change—long-lasting change—that will go beyond what is mandated by laws and policies. Now, before you roll your eyes and say to yourself, “What a Pollyanna!” read on.

If you're a parent, a professional in the field, or a person who acquired a disability, what did you know about people with disabilities before you “entered the field?” The answer, in most cases, is absolutely nothing!

Before the birth of my son, *I* could have been a Scout leader who said, “Oh no, we don't take kids with disabilities.” *You* could have been a regular ed teacher who refused to include a child with a disability in your classroom or an employer who didn't believe adults with disabilities could be competent employees. Yet today I know better and so do you. Why? Was it laws and policies that changed you? I don't think so. *Your heart and mind* were changed by your personal experiences with disability.

When we provide community leadership and influence the hearts and minds of people in our communities, real lives and inclusion for people with disabilities will become a reality. And consider this: as a citizen of my community, I can create change faster and more effectively (insider influence) than any law or program (outsider influence) can. Put yourself in the shoes of someone in your community. Would you respond more willingly to the friendly request of a fellow citizen or to the long arm of a government

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mandate? This isn't rocket science, folks! It is, instead, common sense.

The first step on the road to community leadership is your *presence and participation*. You've got to be there! No one can know what you need unless they know you! Many of us complain that the community "isn't ready" to include people with disabilities. But this is simply hogwash! People in the community *are* ready and willing, but they can't do a thing until they know what's needed, and how can they know until we tell them?

The second step is to *use your existing connections*. You probably already have many contacts in the community, so start there. If you're not connected now or if you don't like the connections you have, make new ones. Volunteer, go to community events, tag along with a friend, or do whatever it takes to meet new people.

The third step involves *reciprocity*—give and take. Community is all about reciprocity. You help others; others help you. If you're out there and people know you by your helpful actions and participation, you'll discover how easy it is to ask for help when you need it. Friends help friends.

The fourth step requires you to *state what you need* for yourself or for the person with a disability in your life. You don't need to beg, nor do you need to get angry and threaten. Both are counterproductive to achieving dignified inclusion and citizenship. Instead, be specific and positive and provide the details about how to accomplish what you need. Don't leave it up to someone else to figure everything out—you're the expert!

The fifth step is being willing to *negotiate*. You may not get everything exactly the way you need or want it. The other person may be unable (not necessarily unwilling) to meet the exact need. Being flexible and working through details to reach a mutually agreeable arrangement can make the difference between success and failure.

The sixth step—and perhaps the most important—is to *expect inclusion*. Many of us have had painful experiences, we're angry, and we expect to be

excluded. We wear our anger like a badge of honor and enter a new arena ready to fight. Arming ourselves with the law, and before taking the time to educate or negotiate, we assault or ambush the unsuspecting person and turn a potential ally into a true adversary. We shoot ourselves in the foot so often, it's a wonder we have any toes! When we leave our anger behind and enter a new situation with hope and an open mind, wonderful things can occur.

Consider that the experiences you have will impact the lives of other people with disabilities in your community. When a person, business, or organization has successfully included an individual with a disability once, they'll know they can do it again! We can truly blaze new trails that will open new frontiers of inclusion in our communities. Typical preschools, park and rec activities, churches, employers, and every other entity can be the beneficiaries of our influence. The sky's the limit!

A recent situation in our family's life illustrates how community leadership can enable people with disabilities to lead real lives. Our 16-year-old daughter, Emily, is enrolled in dance classes at the Starr

Mountain Performing Arts Studio in our small town in Colorado. When a drama class was added, 15-year-old Benjamin was interested in

enrolling, since his goal is to become the first James Bond who uses a power wheelchair!

The folks at Starr Mountain knew me, since I made it a point to be involved in my daughter's dance experience: helping with recitals, talking to the teacher when I had concerns, and so forth. I enrolled Benjamin in the drama class and after paying for the first month's tuition, told the instructor (Jonathan) that because of Benjamin's cerebral palsy, he would need scripts in large print. I added that these should be easy to enlarge on Jonathan's computer, but I volunteered to do it on our home computer if that would be helpful. Jonathan replied he would provide this accommodation.

Each time we took Benj to and from the weekly classes, we casually chatted with Benj and his instructors (Jonathan and Jen) about how things were going.

**The most important step
is to expect inclusion!**

Through this friendly process, we realized we needed to send a tape recorder with Benj to each class so he could have a record of the lessons (the other students took handwritten notes). Benj and his dad began transcribing the recordings to our home computer, and all the lessons went into Benj's drama notebook.

Soon, we learned the class would have a performance at our city-owned Cultural Center. Since my daughter had performed in ballet recitals in this building, I was familiar with it and realized the stage was not wheelchair accessible. About eight steps led from the seating area to the stage. Oops! How would our budding actor perform in a real play in the community if he couldn't get on stage?

After carefully considering several strategies, my husband and I decided on a plan. I called a couple of Eagle Scout troops in our community, told the leaders we might need help building a ramp to the stage, and asked if this sounded like a good Scout project. (You *do* know that Scouts, Kiwanis, and a wide variety of organizations in your area routinely engage in community projects, right?) One Scout leader said no; the other said yes. This was to be our back-up plan in the event the folks at the Cultural Center said they didn't have the money, time, or resources to ramp the stage. An additional piece of this back-up plan was for me to solicit donated materials from the neighborhood do-it-yourself store.

I called the manager of the Cultural Center and made an appointment for a meeting, simply stating that I wanted to speak with her about using the Cultural Center. I did not say one word about my son or accessibility. The Cultural Center is regularly rented out (for a fee) for various events, so it was easy for the manager to assume I was interested in using the Center for a future event.

My husband, Mark, and I brainstormed how we wanted the meeting to go: what we would say and how we would say it, and we tried to anticipate the manager's objections and what our responses would be. We vowed to keep it positive and to use "compliance with the Americans with Disabilities Act" only as *a last resort*. Furthermore, we decided

to take Benj with us so he could participate and learn how to do this for himself in the future, and so the manager could see we were talking about *a real person*.

When the appointed time came, we drove to the Cultural Center with positive attitudes and a picture of success in our minds. The outcome—an accessible stage—was our guiding light. We were determined to not only be successful, but to also develop an ally in Mary, the Cultural Center manager.

Once we arrived, we introduced ourselves and enthusiastically described our daughter's participation in ballet recitals at the Center and our excitement over Benjamin's upcoming performance. Then we detailed the purpose of our visit: have the city build a ramp to the stage so Benj could take his place alongside his drama classmates

during rehearsals and the performance. Immediately, Mary stated that a ramp wasn't necessary since there was a garage door in the rear of the building that was on the same level as the stage. "Your son can use the garage door," she said.

I explained that it wouldn't be effective or appropriate to expect Benj to get to the stage that way, while his classmates would be able to get to the stage from inside the building. I painted a picture of a rehearsal: instructor on stage with a small group of kids while the others watched from the audience area, then the actors trading places and so forth. How could Benjamin truly participate if he constantly had to go in and out of the building through the garage door in the back?

I added that during rehearsals and for the actual performance, it would be almost impossible to expect Benj to use the garage door numerous times during any one time-period, considering the cold and snow on the ground in the middle of a Colorado winter. I politely reiterated that a ramp to the stage from the seating area was the only solution. And then I shut up and waited for her reply. (I really can shut my mouth when I need to!)

With a momentary tightness around her eyes and mouth, and after a long pause, Mary answered that a permanent ramp could not be built because

*A leader is a
dealer in hope.*

Napoleon

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some people who rented the Center needed every square foot of space and the ramp would take up a lot of room (and she was right—it *would* be big!).

My husband jumped in with ideas for a portable ramp. We walked over to the stairs and began discussing different options, specifically a ramp made of piping, similar to the ones used by hotels when they build a temporary stage and ramp during large meetings. I added my hope that a ramp would encourage other people with disabilities to participate in the performing arts in our town.

As we batted around different ideas, the light bulb went off in Mary's head. "You know," she gushed, "if we had a portable

ramp, others could use it, too. We've had some groups who wanted to have beauty pageants here and they needed a runway from the center of the stage out into the audience. If we had a portable ramp system, there are lots of ways we could use it!" I had to resist jumping for joy, but my big smile matched hers.

Mark and I continued our efforts, knowing if you want something done right, you do it yourself! So we asked Mary about the process of actually getting the city to purchase a ramp and she gave us the details. "Tell them I sent you," she added, as we headed over to city hall.

The ramp isn't a reality yet, but it will be. Because of changes in Ben's drama class, the performance has been postponed until the spring, giving us all a little more time to investigate which type of ramp will be best.

Some advocates who wield rights and laws like baseball bats may criticize this method, feeling we shouldn't have to ask or negotiate for access which my son and others with disabilities are entitled to under the ADA. And, yes, angry demands may have gotten

the ramp. In the process, however, I might have made enemies who would despise me and my family, as well as every person with a disability who came along after us. Is there a time when rattling our sabers is appropriate? Of course. In our family, however, we choose that method only if all other efforts fail.

One day, when my son performs on the accessible stage at our community's Cultural Center, his participation will demonstrate that our community is inclusive and that people with disabilities are com-

petent, contributing, participating fellow citizens. And if I look into the future, isn't it highly likely that the contacts made through my son's drama experiences will

When I'm getting ready to reason with a man,
I spend one-third of my time thinking about
myself and what I'm going to say,
and two-thirds thinking about him
and what he is going to say.

Abraham Lincoln

lead to potential employers seeing him as a competent young man when he's ready for a part-time job as a 16-year-old? The positive outcomes are unlimited.

I'm hopeful and excited about the possible ripple effect this may have on people who attend the performance. Won't audience members (who represent a wide cross-section of folks in our community) recognize that people with disabilities can be easily included? And how many families of people with disabilities will realize they, too, can take advantage of the wonderful opportunities in our town?

What can *you* do to provide positive, proactive leadership in your community to ensure people with disabilities enjoy the precious benefits and enriching adventures of citizenship? And what methods will you employ that will ensure success and develop allies at the same time? What attitude, which words, what body language, and what efforts will you bring to the table? Always remember that your actions will impact others with disabilities in your community, for better or for worse. *What legacy will you leave?*