

Our Activism Needs Allies

From the www.disabilityisnatural.com E-Newsletter by Kathie Snow

One of my earliest teachers, the late, great Ed Roberts who was the Father of the Independent Living Movement, taught me and many other disability activists how the Disability Rights Movement both followed in the footsteps and stood on the shoulders of previous movements. The Civil Rights Movement and the Women's Movement paved the way and provided valuable lessons in the quest for equality of people with disabilities.

Great legislative measures have been achieved: Section 504 of the Rehabilitation Act (1973), the Developmental Disabilities Act (1975), the Individuals with Disabilities Education Act (IDEA, 1975), the Americans with Disabilities Act (ADA, 1990), the Olmstead Supreme Court decision (1999), and more.

Fast forward to the 21st Century. In 2017, disability activists stormed the Capitol and legislative offices to protest changes to the Affordable Care Act (ACA - "ObamaCare") and Medicaid provisions that would be harmful to people with disabilities. There's also great concern about proposed changes that would weaken the ADA. So while some progress is achieved, nothing is permanent. Celebrations must be tempered by hyper-vigilance. The crusade continues.

While disability-specific laws/policies *have* generated some improvement, they haven't always achieved their *intended outcomes*. Too many children and adults with disabilities continue to be segregated instead of included. Second-class citizenship and poverty are the norm for too many. Discrimination in employment continues. The list goes on.

Now consider other current movements. During these contentious times, it's been heartening to see today's level of activism on a variety of issues: LGBTQ, immigration, Dreamers/DACA, gun/school safety, voting rights (again), women's issues (again), and more. In some cases, policies and/or laws have been changed; in others, the issues remain unresolved.

The difference between disability activism and the groups mentioned above is stark: these groups have been incredibly successful in gaining widespread support among the general population. Success has been

achieved—in the past as well as today—when those who are *not* marginalized visibly support those who *are*. When white people support the civil rights of brown/black people. When "straight" people support the LGBTQ community. When empathetic people support humane immigration policies. When men support women's issues, and so on. A fellowship is created!

These examples seem to indicate that ordinary people see the injustices and rise up in solidarity. Perhaps they're following the wisdom of the Rev. Dr. Martin Luther King, Jr.: "Injustice anywhere is a threat to justice everywhere." It's also possible that ordinary people recognize the similarities they share with members of a group—"that could be me"—and they're energized to create positive change.

Sadly, there are few signs that disability activism has similarly permeated the consciousness of the general public. Despite the thousands of disability-related non-profits, provider agencies, and/or similar entities, people with disabilities and their families often travel a lonely path. Yes, there are dedicated policymakers and leaders here and there who are valuable allies. But when newscasts showed images of people with disabilities protesting health care issues in the Capitol, we didn't see masses of ordinary people protesting alongside. Thus, TV news viewers perceived that this situation is about Them (The Other)—not Us.

Ironically, as Ed Roberts taught so many, people with disabilities represent the largest minority group in the country (perhaps the world?) and it's the only minority group that is totally inclusive (representing people of any and all genders, sexual orientations, ethnicities, economic levels, religions, ages, etc.). In addition, Ed taught that it's the *only minority group that anyone can join at any time*: at birth, as a result of illness or injury, or through the aging process.

Perhaps one reason disability activism remains relatively invisible is simple: the majority of children and adults with developmental disabilities *are* invisible! Too many are isolated and segregated apart from the

I am an invisible man. I am a man of substance, of flesh and bone, fiber and liquids - and I might even be said to possess a mind. I am invisible, understand, simply because people refuse to see me.

Ralph Ellison

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mainstream, so they have few natural allies. For example, most adults with developmental disabilities aren't in the workforce, so unlike members of other groups, they don't have coworkers, colleagues, and friends (without disabilities) who embrace their issues and are willing to march or protest with them. Ditto too many children with disabilities who are not included in general education classrooms, or participate in ordinary community activities (sports, religious, youth groups, etc.).

The 2017 activism around health care was, and continues to be, a critical issue. But other matters can also be life-changing for children and adults with disabilities. Segregation in public school settings (special ed classrooms). Substandard education. Segregation (special programs) in our communities (sports, religious, youth activities etc.). Segregation of adults in residential facilities and day programs. Unemployment, underemployment, and living below the poverty line. Sexual, physical, emotional, and verbal abuse at rates that far exceed abuse in the general population.

We may routinely see disability activism about Medicaid/health care reform, ending the waiting lists for services, and/or increased funding for disability services. But we don't see rallies or other organized events *for* inclusive education (from preschool through college) and *against* sub-standard segregated special education (which leads to unemployment and poverty years later!). No protests about people with disabilities living below the poverty line or their estimated 75-90 percent unemployment rate. No actions targeting government policies that are *intended* to ensure equality, inclusion, and non-discrimination but that *in practice* result in continued invisibility, segregation, second-class citizenship, and more.

What will it take to change this situation? Children and adults with disabilities and their families need more allies from the general population. It's not enough to depend only on the people already involved in disability issues. And success in this effort will not happen overnight, but if we don't get started now, *it will never happen*.

As parents of children with disabilities, we need to take the time and make the effort to become friends with parents from our children's schools—parents whose children do not have disabilities. We need to join the PTA (no more Special Ed PTAs!) and/or other ordinary

parent groups. Ditto in our churches and community activities (we don't need "Special Needs" programs that further isolate our children). The parents we connect with can become our friends and allies as we work toward inclusion in schools and our communities. Progress will be made only when we get out of the invisibility of Disability World and *become visible* in the Real World. We need to educate others about the issues facing our children and families, especially why inclusion in all areas of life is critical. Inclusion is a moral imperative.

In our efforts to develop allies, it's important not to *start* with disability issues, but to first establish relationships based on common interests. It's also important that we start with whispers instead of shouts.

When my children were young, they attended a wonderful elementary school where all children with disabilities were included in general ed classrooms. My son, Benjamin, was five and in kindergarten; he has cerebral palsy and used a walker and manual wheelchair. My daughter, Emily, was two years older, so I had some

familiarity with school events during the previous year when she was in first grade. And during the Halloween carnival that year, the haunted house was situated on the long ramp/hallway that connected the first and second floors of the school. The entry to the haunted house was near the top of the

ramp/hallway on the second floor; the exit was close to the bottom of the ramp/hallway on the first floor. So after the fun of the spooky sights and sounds of the haunted house, you had to go up a set of stairs to rejoin the carnival in the tri-space on the second floor.

Obviously, my son (and others who couldn't climb stairs) wouldn't be able to enjoy the scary haunted house! So rather than approach the PTO Halloween volunteers and insist the haunted house to moved to a more accessible location, I joined the PTO and volunteered to work on the Halloween carnival. I was hoping to be assigned to the haunted house, but that was a "plum position" and since I was a newbie, I was put in charge of the (lowly) apple-dunking booth. Nevertheless, I got to work.

Quietly. That's how I began. Meeting other moms, learning who was who: Marianne was the mom of Lisa and Stephanie; Margo was the mom of Stephen, and so on—parents are known by their children! The many meetings in September and October were opportunities to get to know one another. And I tried see things from their perspective: how would I feel if a new person tried

We talk about the invisibility of homeless people, of the chronically ill...In these contexts, invisibility is impotence. What is powerful is to be seen.

Kathryn Schulz

to tell the group how to do this-or-that. So I moved gently and slowly, getting closer and closer to the day I would ask, “What will it take for us to move the haunted house so it’s accessible for all?”

Throughout the many meetings, we learned more about each other and our kiddos. We talked, we laughed, we learned about husbands and other family members. At one point, some of the moms began asking me about Benjamin—was he born like that, what could he do/not do, and more. I took no offense; they were sincerely interested in me and my family (and curious, too) and we were now friends! As a bonus, their questions opened the door to a great opportunity for me to educate them about people with disabilities.

As the meetings progressed, I moved gently, slowly, and strategically, preparing for the big day when I would bring up the issue of the haunted house location. Then—lo and behold—the mom in charge of it brought it up on her own! She said that after getting to know me and learning more about Benjamin, she realized he wouldn’t be able to enjoy the haunted house—nor would grandparents who used walkers or someone who used crutches. With remorse, she added, “I can’t believe we never figured that out!” (And perhaps I would have been the same if I had not been Benjamin’s mom.) We then brainstormed where to move the haunted house so it was accessible to all.

Some 20-plus years later, I still get goosebumps remembering that day—what it felt like that someone cared about my son being able to fully participate and be included *without my asking*. And the fellowship I enjoyed with other parents, coupled with all of the school friendships Benjamin made, led to positive changes in the perspectives of many children and adults. When we first demonstrate that we care about other people and their issues, we’ve taken the initial steps in creating a mutually beneficial relationship where they care about us and our issues. Progress *is* possible!

Regarding adults with disabilities, we, of course, need to work toward real jobs for real wages—so that people with disabilities become friends and allies with their co-workers (and rise out of poverty in the process). While there may be many barriers, they’re not insurmountable and progress *is* being made in fits and starts.

There are also smaller steps that can help people with disabilities connect with others to make friends and allies. And as many have discovered, friends and allies can, in turn, lead to opportunities for a real job and more.

Adults with disabilities need to be included alongside people without disabilities in community activities based on their *shared interest*. Consider what might be of interest to an adult with a disability in your community: park and rec activities, opportunities at museums or libraries, karate class, pick-up basketball, photography club, scrapbooking class, cooking club, and the list could go on and on. *Our communities are rich with possibilities!* Our son’s experiences in ordinary activities offers proof that when a person with a disability is engaged with others based on a shared interest, the person’s disability becomes irrelevant. It’s the shared interest that counts and it opens the door to fellowship.

Also, we need to stop pretending that a staff person shepherding six people with disabilities on an outing to the mall represents true community inclusion! And we need to stop worshipping at the altar of bowling being the “sport du jour” for people with disabilities.

Yes, there may be some barriers to deal with, but most are of our own making and so we can unmake them! For example, a person with a disability does *not* need paid staff with him at all times; non-paid volunteers and/or new acquaintances/friends can be called on to assist. Before we decided to trust in the kindness of strangers, my husband and I felt that one of us (or someone who knew Benj well) would always need to be with him. Once we began to trust, Benj enjoyed a new level of interdependence (*we* didn’t have to always be with him). New people welcomed him, helped him, treated him kindly, and often became friends and allies.

The Disability Rights Movement has been going on for almost 60 years—EGADS! We can no longer allow people with disabilities to be the most patient people in the world, waiting, waiting, waiting to live the lives that most people take for granted. Can we afford to let another 60 years go by? If we want change *in our lifetimes*—for everyone who is alive today and for *those not yet born*—we need to generate more allies and become more visible. Time’s a’wasting! People are waiting! Let’s get busy!