



Advocacy and Why it's Important

By: Kieran McGovern

People throw the word around quite a bit, but what is advocacy? The general meaning of the word is to stand up for and defend the rights of oneself and/or others. This could mean contacting elected officials for representation, speaking up at your IEP (Individualized Education Plan) meeting, or checking the mall bathrooms for accessibility. Simply being out in the community -- being seen -- is advocating (disabled people out on their own, imagine that!).

Advocacy is important for all people; old, young, disabled and non-disabled alike. We as individuals are the ultimate guards of our rights... BUT, like most things, there's a right way and a wrong way of advocating.

I would guess that most people (to some degree) are excited by the radical, rabble-raising element of advocacy. This is the fun stuff; the ADAPT (ADAPT is a hardcore, radical disability rights network) protests! People often overlook the fact that these demonstrations, rallies, functions, etc., are the product of hard work behind the scenes (this is why most Independent Living Centers have advocacy teams!). Independent Living Centers (ILCs) are agencies that assist people with disabilities in learning the skills they need to be successful in the community.

An old stereotype that many folks still believe (though it is changing these days) is that people with disabilities are whiny, impatient, selfish, rude and largely uninformed. Some of that is a result of fear -- the fear of the status quo being challenged by people with disabilities who are traditionally considered "less than" everyone else. But to every stereotype is some element of truth. With that said, it's important for advocates (especially those who are young and/or inexperienced) to visualize the change they wish to see before acting. By visualizing change, one needs to think of the improvements they want to see. Dream it and then do it! More importantly, it is absolutely necessary to show respect and the ability to compromise. Being harsh and rude is counterproductive. It won't work!

It's easy to get excited, but we must understand the seriousness of what we do and the impact it has. It is also important to pick and choose what needs



advocacy. Arguing over petty matters is not good advocacy - it is often seen as bitter, dramatic and ignorant. By "petty matters," I mean something as simple as an easily-removable obstacle in a hallway, for example, that you can ask someone else to move. Or things like politically correct disability language... many are unaware that terms such as "handicapped," "wheelchair-bound" or "physically/mentally challenged," are generally thought to be bad. Is it really worth it to get fired up about it if someone does use such a term? No. Why not just calmly let them know the acceptable is "person with a disability"?

When I become aware of a facility (a doctor's office, store or train station, etc.) that is not accessible by the rules of ADA (Americans with Disabilities Act), here is what I do. First, I need to make sure that, say, a convenience store's doorways are, in fact, less than 36" wide, or there are no access aisles for the accessible parking spots. To do that, I would either need to see photographs of the issue or see it in person. Then I write a letter informing the owner/manager of the facility who I am and the organization I represent, as well as the accessibility issue at hand, and possible ways to correct the problem. I do this with utmost respect and courtesy. If that letter goes unanswered, I send another letter, as a reminder, ending with "I expect a response," rather than "I look forward to hearing from you," which would've ended the first letter. If and when the second letter is unanswered, I send a third and final one, with a colder tone BUT NEVER THREATENING LANGUAGE! Here I summarize the two letters I sent before and basically explain that the organization will pursue the matter on our own terms. This could mean writing the Commission on Quality Care or the Better Business Bureau, or contacting an attorney. I ask the manager to call if they'd like to discuss solutions to the problem. This is my way of advocating.

We live in an age where our rights are being stripped from us at an ever-increasing rate. The global superstructure has long discriminated against the disabled, so WE see our rights fall by the wayside at a higher rate than the general population. Those who oppress us count on us to be passive and generally unknowledgeable and whiny. That's why it's important to advocate for equality. By the same token, the goal is INTEGRATION, not SEGREGATION, so it is important to have respect for ourselves as well as the community we represent and the community we live in. We need to appreciate the progress that's been made for people with disabilities in the last 40 years, and remember that cooperation is the best way to create change. Let's keep it real!



Advocacy tip: many government/service entities will claim exemption [that they don't have to follow the rules of the law] from ADA law by a "Grandfather Clause" (that the building was constructed prior to the ADA's enactment in 1991). No such "Grandfather Clause" exists. The only way an entity can claim exemption is if making adaptations would severely alter their functioning, is not readily achievable, or would create an undue financial hardship. 95% of the time, this is not the case.

Kieran McGovern is a college graduate and works as a Systems Advocate at a Center Independent Living in Long Island, NY. Keiren is a hockey fan and enjoys performing music and comedy.

Kieran would love to hear what you think --- please visit the KASA Forums and share your thoughts!