

LEADERSHIP

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QUESTION: “Members in our group have been commenting on certain changes that affect our lives in many ways. Seems as if various government agencies aren't as willing to help as before, for instance, and sometimes we're left with a financial burden we can't handle. Are we in danger of losing some of the rights so many of us fought for?”

ANSWER: Sure. We are forever in danger of losing some of the rights so many of us fought for. The reason this was such a tough struggle in the first place is that there are always those with an agenda they're more interested in than ours.

We have to remind those people that we deserve our hard-earned rights, and we intend to keep them. We don't dare let up.

Taking our civil rights protections for granted has crippled our cause, left us scrambling to re-gain promises lost by our inattention. There have been setbacks in the courts, attempts to dismantle the planks of the Americans with Disabilities Act (ADA), which atrophy the muscle of the main legislation that defends our rights. Now we get to be a part of the faction that is doing its best to put that Humpty Dumpty together again.

Years ago I talked with a Target store manager about making some of his checkout lanes wide enough for chairs, with low enough counters for the people in those chairs to use. He wouldn't hear of it—until one day when I went back to make my final pitch, he suddenly understood. His wife had broken her leg and was forced to use a chair! The guy had to take her everywhere and was telling me with great passion what a huge hassle this was! "Can you imagine," he shouted, "we have to leave thirty minutes early just to get her into the building on time!" You should see that store now--we got everything we asked for and more! There's nothing like a little experience to wake people up. Is there any way we can simulate this kind of exposure in the minds of the decision-makers of the world?

Of course I'm proud of what our polio groups have accomplished. Surely each one of us can drive around in our home towns and see a zoo's "rain forest" that's no longer restricted to the ambulatory; ramps into public buildings, countless curb cuts, accessible parking stalls, smooth, wide pathways. We know there are accessible restrooms and regulation doors and uncluttered aisles and wheelchair theater seats that didn't exist before—all the result of our undying insistence on pulling the ADA together and putting it in action. Others now recognize our right to be here and accommodate our independence. We can't afford to lose any of this to those who seem to have no idea of the necessity for our goals.

For example, when I read that a governing body is attempting to strip us of our self-sufficiency by insisting that only agency workers can provide in-home services, I know it's time to start demanding those legislators get a more enlightened idea of who's in control of my choices here—and it had better be ME, not the agencies.

And what's up with "the scooter issue"? We can only get help paying for equipment used inside the home? Never mind that I can't walk half a block and am imprisoned in my house without money for wheels to get me into the market or down the street. We have to learn to stop these roadblocks to our quest to live independently.

Let's be sure our voices are heard when Medicare or Medicaid guidelines are put in place or changes are made. Let's be listened to when health insurance and medication costs are legislated. How can we get our message across?

Unfortunately, occasionally the problem of not expressing our might is compounded by some of us in the disability community who fail to see ourselves as playing a role in our own destiny. Perhaps we remember a time when folks with disabilities were regarded as children, not allowed to think for themselves and make their own decisions. We may recall a past when others attempted to make us feel less-than, unworthy of wielding the power that is ours. Guess what--those days are gone.

The squeeze is on. As luck would have it, we're moving swiftly into next year's elections. This summer could be the perfect time to help our groups dive in. Dispelling the notion that we don't count should be at the top of the list.

Leaders can:

- Bring the issues to meetings for lively discussions.
- Hand out a list of candidates, naming where they stand on the issues, spelling out their disability records, and discussing the consequences of our votes.
- Provide candidate addresses and phone numbers for members who want to let them know in person how they feel about issues.
- Explore ways the state handles registering to vote in order to make it as simple as possible for everyone to participate.
- List accessible polling places (for members who don't want to give officials the chance to say they don't need accessible polls because people who are disabled never come there) and arrange car pooling if necessary.
- Familiarize members with the voting options available.
- Discuss why it's so important for polio survivors to retain our rights.

Since most decision-makers are either elected or appointed by those who are elected, voting becomes paramount. The message: Want to keep those hard-gained rights? Then REGISTER and VOTE!
