

# Guest Post: Start Small, But Get Involved

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Disability advocates at the Utah State Capitol

*Editor's Note: We are gearing up for Disability Advocacy Day! In honor of the event, guest blogger Kirsten Barraclough wrote this reminder to get involved!*

In her memoir *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, Judy Heumann writes, “our government is constantly changing. It was created by groups of people and it gets changed by groups of people.” Then she asks rhetorically, “Do we want to be the people creating the government we believe in, or do we want to be the people simply accepting whatever comes our way?” (204).

This is a thought-provoking question. According to U.S. Census Bureau data from 2021, nearly 45 million people in America have a disability. That’s 13.6% of the population. So, how can we ensure that the voices of people with disabilities are heard in the legislative process?

Getting involved in disability policymaking can start small. First, it is important that people with disabilities themselves realize they can speak up for themselves and have opinions. Learning how to communicate well with others is key to getting your point across effectively. Then you can educate yourself on current laws and policies. As you learn about issues that you feel strongly about, you might want to write letters or have meetings with your legislators.

When you contact elected officials, here are some pointers. Tell your story and state your position in a clear and concise manner. Prepare a few main points. Do your research beforehand. Find ways to personalize your interaction if you can. And remember to be respectful.

I have a friend whose son has Spinal Muscular Atrophy (SMA). As his mother, my friend has gone to Capitol Hill in Washington, D.C. several times to advocate for him. (Her son did not come with her because he was under 18 years old, but he has expressed interest in doing it in the future). Her work has included advocating to get SMA added to the list of diseases recommended to be a part of newborn screening and to get more funding for rare diseases, as well as advocating for legislation to make travel (specifically air travel) more accessible for people with disabilities. Efforts like this start with people who have personal stories, see a need, and decide to do something about it. And, even if you don’t get involved nationally, you can certainly become involved locally.

For a few years, I served as the chairperson of a Youth Advisory Council for the Kentucky Office for Children with Special Health Care Needs. It was an eye-opening experience. Our council provided feedback on how the office could improve the lives of people with disabilities, particularly as they transitioned to adulthood. At the meetings, policies and grants came up in the discussion occasionally. It was a good experience for me to be involved in my community.

Judy Heumann wrote, “We—all of us, and especially marginalized people—need to work together. In the broader civil rights movements disability was and still is absent. Visible and invisible disabilities cut across all minorities. ... We can’t be selective about which marginalized group moves forward. At the end of the day, we all need to be moving forward together.” In other words, success hinges on cross-disability coalitions working with non-disabled allies. Power comes from becoming united and focusing on our common goals and purpose.

It might feel overwhelming to think of getting involved in political matters. My advice would be to start small. Look up the names of your legislators. Research issues that impact your life as a disabled person. Ponder how sharing your personal story might help inspire change, or at least help legislators think about different perspectives. And if you band together with others to work together for change, that’s even better. At the very beginning of her book, Judy Heumann writes, “Some people say that what I did changed the world. But really, I simply refused to accept what I was told about who I could be. And I was willing to make a fuss about it.” In the next paragraph, however, she emphasizes that “it wasn’t actually an ‘I,’ it was a ‘we.’ For any story of changing the world is always the story of many. ... This is my story, yes, but I was one in a multitude” (3).

Each of us is only one person. But each one matters. As we participate in the political process, we add our voices to the multitude. And multitudes can change things, together.

## Resources

[Utah Developmental Disabilities Council](#). Established by Executive Order of the Governor of the State of Utah, the council advocates for, and strengthen leadership skills in, individuals with disabilities and their families.

[Utah Statewide Independent Living Council](#). This organization promote the full inclusion, independence and empowerment of people with disabilities.

The [Utah Disability Law Center](#) is a private, non-profit organization designated by the governor as Utah's Protection and Advocacy agency.

The [Legislative Coalition for People with Disabilities](#) advocates for public policy affecting all people in Utah who have disabilities.

The [Utah Parent Center](#) helps parents help their children, youth and young adults with disabilities and special healthcare needs to live included, productive lives as members of the community.

You can find your Utah legislators on the [Utah State Legislative District finder](#).

You can find your U.S. elected officials on [U.S. elected officials finder](#).

## Work Cited

Heumann, Judith. *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*. Beacon Press, 2020.