

Winter 2019 | Theme: Disability Advocacy

In this issue, people who are involved in disability advocacy describe how and why they engage in advocacy with people who have disabilities and the challenges they face.

Addressing Disability Stigma by Leading Personally

by Gerri Yoshida Japanese American United Church (RCA-United Methodist), New York City

Mana Hashimoto and I started working together in 2014 to find new performance opportunities for her as a blind choreographer and dancer. This led to my profound respect and enthusiasm for Mana's commitment to dance without sight. I saw her desire to make dance accessible to people with visual impairments through audio descriptions of her dance, preshow walk-throughs of the dance space, and allowing audience members with visual impairments to feel her props and costume so they could imagine and participate in her performances.

In Japanese and Asian American cultures, there is strong shame, stigma, and silence around disability issues. However, God led Mana to advocate for the needs of those with visual impairments, and that helped her rise above helplessness and despair. In fact, four years ago, our church, the Japanese American United Church in New York City, celebrated its first Disability Awareness Sunday. By focusing on various physical and mental disabilities, we hope to make conversations more accessible.

"It is important for individuals to become independent and play a role in leadership," says Mana, who serves as our church's disability advocate. "Often people look at persons with disabilities as someone who needs care, but like any other individual, we have potential and gifts. Inclusion doesn't mean one side supports the other; it means both sides are supporting each other."

Attending this year's RCA/CRC Disability Leadership Training empowered us to more boldly champion the belief that "everybody belongs, everybody serves." We desire to include and provide a sense of belonging to people who are isolated due to aging and illnesses. We want to train our children and young people to be sensitive and proactive. Most importantly, we recognize that people with disabilities deserve to have their independence recognized and respected. Through contributing their gifts, leadership, and interests, they enrich the whole body of Christ and extend God's kingdom work.

Making a Place of Welcome for All

by Cara Milne Classis Alberta South/Saskatchewan (CRC) regional advocate

My life is a reflection of Philippians 4:13, "I can do all things through [Christ] who strengthens me."

There is a big difference between being a guest and belonging. As a speaker and author who specializes in community building for people with disabilities (see www.mpoweredplanning.com), I am often asked by churches how to begin to include people who are vulnerable. Although there is no one perfect way, there are specific things we can do to help create an atmosphere that includes everyone:

- Language: Always keep in mind that a person is first, and their disability or labels are secondary. We want to refer to people with disabilities, not disabled people. Also, avoid a high-pitched or condescending tone of voice. When we talk to adults as if they are babies, we increase the stereotype that they are childlike.
- Respect: Aim to get to know people—their interests, roles, and hobbies. When conversing with a person who has a disability, talk as you would to any other person.
- **Contribution**: No one wants to be a charity, so we need to give people a chance to genuinely participate and contribute in congregational life. Support people to give back in any way that fits for them, whether as a greeter, usher, coffee maker, or whatever else.

• **Don't take over**: A support person or volunteer should not take over everything. For example, a Sunday school class might want to include Jessica, but then assume that her volunteer will do everything for her. Volunteers should not help Jessica make every craft perfect. Instead, they need to focus on the importance of having Jessica connect to her peers. Focus on relationships first, and skills or academics second.

Remember that it is often a slow journey, but start where you are. In the end, we are all better when we all belong.

My Path to Disability Advocacy

by Sonrisa Cortes RCA Disability Concerns intern, Western Theological Seminary, Holland, MI

My most beloved role as an advocate has been working as a home health aide for Amy*. Amy has cerebral palsy and some cognitive limitations. She uses an electric wheelchair and has limited use of her arms and legs. Amy has high anxiety and does not enjoy changes in her routine, but there are afternoons we leave her house and go into the community. These days are always extra special.

But Amy and I are not always treated respectfully: Amy is often met with baby talk and comments on "how well she is doing" for simple tasks like driving her chair. She's been told how "cute" she is simply for shopping in the grocery store.

These people pity my friend. In reality, they are the ones I take pity on. They do not know how talented Amy is in finding the perfect song to match the mood, nor how loving she is. They don't know what a great aunt she is to her nephew, or how smart she is. To them, Amy is a disability, not Amy who happens to have a disability.

My time with Amy reminds me that raising awareness about disability is something I am passionate about, and disability advocacy has a long way to go. I advocate for friends and for strangers I have yet to meet. I strive to make my communities more inclusive and welcoming to all people. This is why I have dedicated myself to become a disability advocate.

*Name changed for privacy

Editor's Note

The Art of Advocacy

Although I've lived my entire life with a disability, it wasn't until my mid-30s—when I agreed to serve on the board of directors for the local Center for Independent Living—that I was confronted with the need to begin advocating for other people with disabilities. That was nearly three decades and three job changes ago, and I'm still learning what it means to be an

effective advocate, even in my tenth year as RCA coordinator for Disability Concerns. Disability advocacy is more art than science.

I can think of at least three components that are great assets for disability advocates—awareness, humility, and courage.

- Awareness means becoming educated about a particular disability-related issue and empathizing personally with those who are feeling excluded because of their disability.
- Humility acknowledges that I do not understand all the issues at work. Even if I think I know exactly how a situation can be corrected, it's likely that I don't understand everything involved.
- Courage is a willingness to "put myself out there" and risk opposition for the good of others.

Experience also comes in handy, but it's not as important as awareness, humility, and courage. Receiving affirmation and support from others are gifts that keep on giving, especially from those who have been excluded; keep in mind that their pain has been lessened by your efforts, regardless of whether the desired change actually is made to your satisfaction.

Finally, reading the stories in this issue submitted by other disability advocates gives a shot in the arm to my own awareness, humility, and courage. I'd love to hear yours.

Upcoming Themes

Spring 2019—Mental health and spiritual practice. How does living with a mental illness shape our faith and spiritual practice? As people who belong to Jesus Christ—body and soul, in life and in death—where do the rhythms of mental wellness, devotional life, and personal discipleship intersect? Please send us a note (not to exceed 400 words) about your experience by February 7.

Summer 2019—Down syndrome

Do you or a loved one have Down syndrome? Please send us a story (400 words)—whether a joy, a challenge, a loss, or a prejudice you've experienced—by April 8.

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