

Opening Words

Charleston Unitarian Universalist Church

8/14/16

Adaptation of a poem from Likrat Shabbat, a Sabbath prayer book:

May our door be wide enough to welcome all who yearn for love, all who long for fellowship.

May it welcome all who have cares to unburden, thanks to express, hopes to nurture.

May our door be narrow enough to shut out pettiness and pride, envy and enmity...but wide enough to accept those who wish to find a home inside.

May its threshold be no stumbling block to any who desire what we offer here.

May our door reflect the welcoming hearts of the family of people who dwell within.

May those who enter find healing and joy, and may those who exit carry our loving message out into the world.

May our door be, for all who enter, the doorway to a richer and more meaningful life.

Amen

Throw Wide the Doors

Janice Wald Friedman

Sermon for Unitarian Universalist Church

Charleston, SC

8/14/16

Good morning! I want to thank you all, and especially, Bernadette, for inviting me to address you this morning—and for allowing me to choose a topic I'm passionate about.

By all accounts, this church is one of the most inclusive in Charleston, and I was told that I'd be preaching to the choir. But we can always aspire to a higher rung on the ladder. In any choir, there are all levels of education and experience, and understanding of things such as sight-reading, music theory and breathing techniques. It's the same when we

speak of Disability Rights and integration. Even when I speak to groups exclusively comprised of people with disabilities, I have to keep in mind that there are multiple levels of understanding about disability. I can't take for granted that my audience knows all the information I have to present just because they happen to have disabilities.

Thinking about the enormous success of this church family in making everyone feel so welcome, you may wonder why this sermon topic is even necessary. It's necessary because we can always take inclusion one step further. We need to keep educating because, for people with disabilities, our work is never done.

It's one thing to embrace a long time member and friend who becomes disabled, as I know you have done several times. But there's always the possibility that someone new with a significant disability will come through the door, and it might be helpful to understand their perspective on how to best help them feel comfortable enough to want to join the family. Of course, what I want to share with you will apply to life outside of church, as well.

Most, if not all of us, at one time or another have felt uncomfortable in the presence of someone with a disability. We often don't know what to say or where to look. We worry that we'll say or do something embarrassing or hurtful without meaning to. We don't know whether it's OK to ask questions or if we should even acknowledge that there is anything unusual about them.

So many of us see a disabled person and think "Oh, that poor thing—I could never live like that!" or "There but for the Grace of God go I." or "I wonder what's wrong with him."

We marvel at how courageous and inspirational people with disabilities are. We may feel guilty for complaining about having to do things that they can't do, especially if we catch ourselves doing it in their presence.

We may wonder if their disability confers special powers which allow them to live with such difficulties. We sometimes rush to help out, to try to "make life easier" for them, even though we really have no idea what their needs are...like the classic cartoon about the Boy Scout who drags the old lady across the street over her protestations that she's just waiting for her son to pick her up at the corner.

These examples of the way we deal with disability, called the Pity and Pedestal models, are very common. Many of us don't really know what to do with the feelings, and even fears, we have about disability. So it's tempting to emotionally distance ourselves, both from our feelings about disability in general and from some disabled people, as well. So we tend to label the person "different," avoid engaging with them, and project our fantasies and uncertainties about disability onto them.

We're certain the Pedestal paradigm must be preferable because surely our friends with disabilities would rather be inspirations than pitied, right? Well, some may, but think about what happens if we are put on a pedestal: We are separated from society, defined by others, and held to a higher standard—and the higher up we're placed in the estimation of others, the farther and harder we can fall. It's a lonely and scary place up there! There's absolutely nothing about living with a disability that should evoke either of these paradigms. We are each just doing what we need to do to make a life for ourselves. If we ascribe to the social model of disability, which most of us do, we know that the barriers and roadblocks that society places on us are much more disabling than anything our bodies or minds throw at us.

If you've ever felt discomfort around people with disabilities, just know that that's part of the innate nature of human beings. It's difficult to fight these feelings, especially because encountering people with disabilities reminds us of our own vulnerability, and that can be frightening. But, it's relatively easy to educate ourselves about disability issues and to learn to see past the disability so that we truly see the person.

It's important to understand, if we are to fully accept those with disabilities into our religious communities, that the population of people with disabilities is no more homogenous than any other group. We each have our own opinions, biases and judgements; we may or may not associate with others with disabilities; we may join groups of people with similar disabilities for support and acceptance; or we may choose mainly friends who don't have disabilities. Just like everyone else, our lives reflect what works for us. We do, however, really enjoy being with people who "get it." "Getting it" is such an important concept which greatly influences our choice of friends, and it's worth taking the time to explain it. So what does "getting it" mean? It means thoroughly understanding how

disabled people want to be seen, treated and understood. It means not trying to put your own spin on our lives. If you “get it,” that means you see me, you hear me, and you accept me as I am.

The Disability Rights Movement, which was formed over sixty years ago, has been most influential in the full inclusion and integration of people with disabilities into our communities. But even with the support of the Movement, it has been an uphill battle to ensure the civil rights of people with disabilities, and the struggle continues.

It may surprise you to learn that the single most important factor in securing equal rights and equal access for people with disabilities is language. This is because language has a profound effect on attitude and attitude determines success. Many people today disparage politically correct language as being either too aggressive or too touchy-feely. But when language works against our dignity, autonomy and independence, I believe we each have a right to ask that we be spoken to and about in such a way that we don't feel threatened by the language others use. Our houses of worship must be safe spaces for us, on all levels, so that we feel secure enough to make them our second home. If “love your neighbor as yourself” doesn't take us into account, if people don't “get it,” then a vital element is missing...and we feel it.

Kierkegaard said “If you label me, you negate me,” which is a concept that applies perfectly to the disability community. The operative word in this sentence is “you.” None of us enjoys being labeled by others. If I simply label you as a Unitarian, I'm only taking into account that one aspect of who you are, and everything else about you falls by the wayside, especially those aspects of you which truly speak to the core of your being. When I label you, I put you into that box of Unitarians...or red-heads...or lawyers...or quadriplegics. And doing that, I negate everything else that makes you unique. And what a disservice I do to you—and, by extension, to myself, because, having defined you in my mind, I may never take the time to get to know you.

Every major religion has within its teachings a version of The Golden Rule. In Judaism, we put a slightly different spin on it: “That which is hateful to you, do not do to others.” The emphasis here is on others and, as such, underscores the purpose of my talk today. We should certainly ask others what, specifically, is hateful to them, but, by and large, we

know that if we don't like or accept a particular treatment, others probably won't either. This applies to people with disabilities in exactly the same way it applies to everyone.

When I speak of and advocate for and with people with disabilities, I'm talking about one of the largest minorities in the world, comprising fully 15% of the global population—one billion people! We make up 20% of the population of this country alone—1 in 5, or 55 million people. It is the only minority that anyone can join in the blink of an eye. And, if we live long enough, 100% of us will have some sort of disability. Many people, such as myself, have invisible disabilities, so we have to assume that we know more folks with disabilities than we realize. It's easy enough to reach out to people with visible disabilities, once we get past our qualms and resistance. But we also need to make it clear in our programming and outreach materials that we are equally open to accommodating folks with disabilities that are not so obvious.

Everything we do to make our churches, synagogues, mosques and temples fully accessible to people with disabilities is an investment in our own futures and those of our friends and family. Not only that, those accommodations also make it easier for many who don't yet have disabilities. Consider how much easier it is for families with small children in strollers to use curb cuts and ramps than to constantly be lifting or lowering those strollers up and down curbs and steps. Think about how ramps make walking to other levels easier for many people who just aren't fond of flights of stairs. Installing paper cup dispensers at drinking fountains makes it easy not only for wheelchair users, but short-statured people and small children to help themselves to a drink. Lever-shaped door handles and automatic door openers, which can be operated with elbows or fists, work equally well for people with limited hand and arm strength and for people carrying too much stuff in their arms. In so many ways, accommodating folks with disabilities makes life easier for all of us.

Disability doesn't necessarily refer only to a condition someone has, but also to the stumbling blocks society places on us via infrastructure and architecture. On a level playing field, barriers disappear and disability almost becomes a non-issue. In a place of worship, if the doors are wide enough, the floors are level, ramps, lifts and elevators are employed, and other necessary accommodations are instituted, no physical stumbling

blocks remain to make those with disabilities feel unwelcome. And, often, these are much easier fixes than we might imagine.

Oddly, when the Americans with Disabilities Act of 1990 was written, religious institutions were purposely excluded from the laws governing access. Why? Because it was assumed that religious institutions, of all places where people gather, would want to do the “right thing,” based on that “Love your neighbor as yourself” thing. Well, that has not been shown to be the case. Here we are, 26 years into the ADA, and sometimes the most difficult accessibility issues have involved religious institutions, often excused by citing financial deficits. These excuses show a lack of understanding of the concept of reasonable accommodation. I’ve also heard “But, we don’t have any members with disabilities.” OK, just don’t get me started on that one! If you build it, they will come! If a church or business needs help with accessibility, there are many of us around who are familiar with the ADA Architectural Guidelines, or ADAAG, who can help figure out less costly and more efficient solutions.

This leads me to the single most important thing you will hear today, at least from me: the Disability Rights Movement embraces a concept which means everything to people with disabilities: “Nothing About Us Without Us!” People with disabilities expect and deserve to be invited to the table when anything that affects or benefits us is the topic.

Making decisions and plans for others without their input, no matter how well-meant, not only strips them of their dignity and autonomy, but it wastes valuable resources, time and money. It’s so much easier to invite us to participate in the discussion.

Kathy Snow, author of the wonderful guide to interacting with people with disabilities called Disability is Natural, says “When you see, meet or think about a person with a disability, presume competence.” No matter how significant their disability, you can never tell by looking at someone what their level of intelligence or ability actually is. It’s a common misconception that if someone has a developmental or, especially, a cognitive disability, they are not capable of making conversation, much less decisions about their own lives. But it’s important to give everyone a chance to speak for themselves. Regardless of our preconceptions we must invite them in, welcome them, and then, most importantly, invite them to join the conversation. Invite them to share their needs and

ideas—and their skills—so that we can learn how to best help them integrate into our faith communities.

This might be a good time to pass along a few often overlooked or misunderstood bits of information about interacting with people with various disabilities. Maureen and Todd will share some of this important information pertinent to their own disabilities in a while, but let me briefly touch on a few others. This is far from an exhaustive list, but these are some of the things many people with disabilities want you to know.

When interacting with anyone with a disability, don't be afraid to ask if you don't understand something about them or something they've said. People with speech disabilities know that they aren't always easy to understand, and they would rather have you ask for clarification than pretend you understood them. Everyone has their own preferences about how they want to be helped—if at all. And, while it may be uncomfortable for you to stand by and watch while someone appears to struggle, the struggle is theirs to accomplish, and they'll let you know if they need help. Before attempting to pick up a person who has fallen, ask what the best way to do that is. If a person uses a wheelchair, they know how to get the chair in and out of a car, and do it on their own all the time, so don't feel you have to help them unless they ask. It's fine to make the offer, but if they say no, respect that.

Blind people are usually quite adept at getting around with the help of a cane or guide dog, and, unless you perceive imminent danger that they or their dog somehow miss, it's not necessary to mention every obstacle you see coming up in their path. And remember that just because someone is blind, it doesn't mean they can't hear or aren't aware that you're there. No need to raise your voice. If you want to be sure they know you're talking to them, just say their name or touch them lightly on the arm to get their attention. And, even though you assume they'll recognize your voice, it's a good idea to greet them with "Hi, John, it's Janice."

When speaking with a deaf person, position, lighting and volume are good things to think about. Again, raising your voice is not necessary, and is often detrimental. The important thing is to speak slowly—though not exaggeratedly so—and distinctly. Many deaf people

read lips, so remember to position yourself directly facing them, with the light on your face, not behind your back. Glare is the enemy of lip-readers!

If there is one pet peeve that is almost universal across disability lines, it's when someone who doesn't know us directs their questions and comments to our companion rather than to us. It's happened so often when I've been out to eat with blind friends that I've stopped counting. The first indication that there's a teachable moment on the horizon is when the server asks me "What will she have to drink?" I usually redirect by finding something fascinating to look at elsewhere and remain silent. Then my friend will say, sometimes pointedly, "SHE will have a glass of water." I've even had servers try to hand me my friend's plate rather than set it in front of him themselves. So remember to direct your comments and questions to the disabled person even if you don't think they are capable of answering.

With the advent of PC language has also come confusion and some contentiousness, both in the general community and in the disability community. As I've mentioned, the disability community is no more of one mind than any other group, and there are as many acceptable and unacceptable standards of language as there are people with disabilities. But sensitivity is a two-way street and if people with disabilities want to be treated and spoken of with sensitivity, they must be equally willing to treat others in a sensitive and patient manner. Since acceptable descriptors do tend to change over time, the best advice I can give to the temporarily able-bodied among us is, if your heart is in the right place, most people with disabilities will be patient guides to what they need to hear from you. And to the disability side of the conversation I always urge patience, letting go of dogma, educating with kindness, and, realizing that we can't know what we don't know.

So, here is the short list of what, today, are considered unacceptable terms in the disability world:

- Handicapped is always one of the biggest triggers, because it represents the concept of a burden...such as a golf handicap given to a less adept golfer...and who wants to be defined as a burden? Say disabled person or person with a disability instead.

- Special needs is an especially heinous description, especially because adults use it to refer to children—or those they think of as children—without their permission. “Special” can never be defined as meaning anything other than “separate.” It may sound sweet, but it actually represents one of the worst nightmares of people with disabilities...separation and exclusion. When we use the term, we are saying to a disabled person, usually a child, “You and your needs are ‘special’ and that makes you different from everyone around you.” Believe me, they know that! “Special needs” is a concept invented by parents and teachers, not by people with disabilities, and is not acceptable to adult members of the Disability Community.
- The terms “confined to a wheelchair” and “wheelchair bound” have been replaced by wheelchair user—a wheelchair means freedom to a person with a mobility impairment...the furthest thing from confinement.
- Any derivation of the word retarded to mean a cognitive disability has been universally rejected as having no positive connotation whatsoever, and has no place in our lexicon. It’s so reviled that most people with disabilities won’t say it at all and just call it “the R word.”

There are always going to be people with disabilities who prefer some of the less accepted terms, and that’s fine, as long as they don’t impose them on others who are put off by them. I had a friend who was blind, who had no problem with being referred to as handicapped. But most of my friends who are blind don’t appreciate that and would prefer us to just refer to them as blind, though some prefer visually impaired. However, words that try to skirt the issue of disability, such as challenged, differently-abled or impaired, are just sugar-coating and are usually rejected. But personal choices are entirely up to the individual, and we should attempt to accept those choices, and respect them, while realizing that that word may not be acceptable or comfortable to the next person we meet with a similar disability.

Keeping in mind what I said was the most important concept you would hear from me today—Nothing about us without us—and the most important aspect of the dialogue with people with disabilities—joining them at the table with our hearts and minds open—there will be no reason to fear interacting with them. Remember, each of us can easily become

the next member of this rapidly growing minority, so I encourage you to learn from the current population, work to assure that our cities, towns and facilities are accommodating to everyone, open your hearts and minds and throw wide your doors. We all have much to gain from our relationships with each other, and isn't that one of the main reasons that we come together in religious institutions after all?

Thank you for opening your hearts, minds and doors to listen, understand and accept our message today. And now I'd like to call on Maureen Kelly and Todd Frech to share some words from their own hearts with us.