

Non-Apparent Disabilities

Sermon by Rev. Helen Murgida, Ed.D.

September 25, 2022

Welcome! It is so good to be with you in person or through YouTube participation. One Sunday a year is dedicated to our Accessibility and Inclusion Ministry or AIM. AIM is a work in progress that embraces our FRS Mission and Unitarian Universalist Principles. Our principles are not dogma or doctrine but serve as a community Unitarian guide that we choose to adhere to.

Our FRS Mission tells us to

Come as you are,
Journey together in love,
Act with courage,
Transform our world.

My words today draw from our First Principle of Unitarian Universalism: The inherent worth and dignity of every person, and our Second Principle: Justice, equity and compassion in human relations.

What Is AIM?

FRS AIM functions with guidance and support from Rev. Rebecca and we are in partnership with the UUA. An inclusive ministry such as AIM is not a program. It is not about creating a special class or a separate ministry or even identifying "the disabled" as an object of ministry. It may be summarized in the motto: "ministry *by* and *with* people with disabilities," in contrast to "ministry *for* people with disabilities." The purpose of AIM is to welcome, embrace, integrate, and support people with disabilities, both visible and non-apparent. It is about "Making Room!"

AIM Projects

Last year the focus was on accessibility and inclusion issues that were identified by FRS members regarding the interior and exterior church buildings and grounds. We have an email list of people who are interested in receiving information and attending monthly Zoom meetings. We completed a series of accessibility check lists provided by the Unitarian Universalist Association (UUA) and brought this information to Rev. Rebecca; Rob Authier, Director of Church Operations; and the Parish Board. There is a brief summary of the status of last year's projects

available at our AIM table located to the left of the lift when you exit.

On-Going Projects: Advertising accessibility to large print Orders of Service and hymnals, sound amplifying headphones, consistent signage, and adjustment in color and font in the Orders of Service, Steeple newsletter, and website. We are working on having reserved parking available on Sunday mornings directly in front of the church for drop-off and pick-up, and for those with limited mobility.

Long-Term Projects: Working with the City of Newburyport to add more curb cuts, improve access to current curb cuts, replace the bricks and curbs on the city sidewalk, add create additional Handicapped Parking spots on Unicorn Street.

Future Proposed Projects: To install automatic door openers on the side vestibule entrance and Lower Meetinghouse entrance. Also, have a large screen TV and necessary electronic equipment to use in the sanctuary for live Zoom accessibility for special occasions, like guest speakers and congregational meetings.

The book *My Body is Not a Prayer Request: Disability Justice in the Church* by Amy Kenny deeply moved me. Amy is a well-published disabled scholar and Shakespearean lecturer. This is a fabulous read that had me laugh and be aghast at the same time. She listed suggestions that were recommended by members of her church community as treatments for her disability such as, "Put garlic in your socks." And "Try jogging. After a while your legs will remember how to walk," or "At least you're only physically disabled," or "At least you've inspired others," or "You're too pretty to be disabled," and "God needed a special angel."

In the dedication of her book, she writes: "For every disabled person wondering whether you fit in, fretting that you are too much. You, with your canes, crutches, Chemical sensitivities and CART, which is a method to provide access to spoken communication for people who are deaf, hard of hearing, or who have certain cognitive or learning impairments, all of you are worthy of

Non-Apparent Disabilities

September 25, 2022 page 2

belonging. You are enough.”

She was interviewed on the Denison University Forum “Is the Church Ableist?” Her “Church” applies to any denomination. She begins by quoting Talila A. Lewis’s definition of Ableism: “a system that places values on people’s bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity.”

Kenny states “It is not my inability to walk or stand that disables me, rather. I am disabled by the fact that buildings are structured with stairs, narrow hallways, and curbs, making them difficult for me to access on wheels. She continues: “By either age or accident, most people will experience some form of disability in their lives... We, the disabled, bear prophetic witness about what is true about the fragile human condition. If only the church would listen to us.”

Non-Apparent Disabilities

The impetus for me to pursue the topic on non-apparent disabilities came from a series of seemingly unconnected events. The first occurred when I was measuring threshold accessibility in our FRS doors, specifically our handicapped accessible doors. The one on the side door to our vestibule meets ADA standards. The door on the lower-level entrance to offices, meeting rooms, rest rooms, and the lift do not meet our requirement for independent wheelchair access. My thought was “but it’s only ½ inch off!” I was shocked by my instantaneous neurotypical ableist reaction – it’s okay for me, so it’s okay for someone using a wheelchair!

We all know that thresholds are a boundary separating two distinct places, in this case, coming from the outside into church. I am a person of thresholds, which I cannot just pass through; I need to sit and pause. I need to notice, identify, ponder, plan, and slow down to appreciate what is behind us at FRS, the wonderful accomplishments, while naming what is ahead of us.

This was my “aha” moment, my “threshold” moment, where my intellect and intuition collided. I feel strongly that it is time for our FRS community to engage in learning about non-apparent disabilities. It is not always a

comfortable topic for a variety of reasons which we will explore this morning.

What are non-apparent disabilities? They are disabilities such as mental illnesses, learning and attention issues, some physical disabilities, neurodiversity, and many other disabilities that are not apparent. It is estimated that 10 percent of people in the U.S. have medical conditions which could be considered non-apparent disabilities. Ninety-six percent of those people who live with chronic medical conditions live with conditions that are non-apparent. They do not use a cane, or any assistive device, and act as though they don’t have a medical condition.

Let’s look at terminology. “Non-apparent disabilities” means that the disability is non-apparent, and it does not imply a negative connotation. It is the terminology that is more acceptable within the disability community whose position is that disability is a strength and it does not matter what type of disability someone has.

We will not use the term “hidden disability” which implies that the person with the disability is purposefully withholding this information. There is a difference between choosing not to self-disclose versus actively hiding it.

We will also not use the term “invisible disability.” For some people with disabilities, this term is offensive. It suggests the person is not visible or that you cannot discern that a person has a disability, which is not always true. Many with recognizable physical disabilities also have non-apparent disabilities.

This is a topic currently being addressed within the UUA and Unitarian Universalist Ministers Association (UUMA). They are offering a series of webinars on “Neurodivergence for Religious Professionals.” Both Rev. Rebecca and I are attending. The series was developed in partnership with the neurodivergent presenters who are UU ministers, heads of religious formation, and youth groups.

I was impacted by the book *Disability and the Church* by Rev. Lamar Hardwick. By “Church” he means all Christian church denominations. Rev. Hardwick talked about the importance and duty of a minister’s preaching about broadening the borders of the church, about building real

Non-Apparent Disabilities

September 25, 2022 page 3

community-changing church culture, learning how to do ministry with people *with* disabilities, not doing ministry *for* people with disabilities.

He states, "What seems unthinkable becomes thinkable...Once that realization has emerged, you can either honor it or ignore it, but you cannot forget it. What has become known cannot become unknown again."

He self-identifies as black, neurodiverse, and the "Autism Pastor" of his Tri-Cities Church in Georgia. At age 36, already married, ordained, and serving as a pastor, he diagnosed himself as having the autism spectrum disorder Asperger Syndrome. This was after the birth of his son who was tested and diagnosed as having autism. He now understands why for many years he had struggled with interpersonal relationships and social anxiety. His threshold was dramatic.

During our process of examining our church for accessibility, I experienced an "aha moment" while measuring thresholds. One of my tasks was simple. Use a tape measure to see if the threshold on the side door to the vestibule and the lower entrance doors did not exceed $\frac{1}{4}$ inch allowance to go over the threshold to enter. Our upstairs door is fine; the lower door entrance exceeds $\frac{1}{4}$ inch. My first thought was "but it's only $\frac{1}{4}$ inch!" Yes, it was fine for me from my neurotypical ableist perspective, but not for someone using a wheelchair. The fact that a door is a threshold between two spaces makes this symbolism work well. What's a metaphor for a door? A door can be a symbol of opportunity or one of imprisonment. A door or doorway symbolizes the transition and passageway from one place to another. A door is often used to symbolize the passage from one world to another in religion, mythology, and literature.

The amount of information that is available on non-apparent disabilities is huge. I will briefly describe six categories of non-apparent disabilities giving only a few examples in each:

1. **Mental Health Conditions:** There are more than 200 classified forms of mental illness. These conditions can make it hard to relate to others and may affect everyday functioning: bipolar disorder, depression, anxiety disorders, and attention deficit hyperactivity disorder (ADHD)

2. **Autoimmune Disease:** There are more than 80 different autoimmune diseases with symptoms ranging from mild to disabling
3. **Chronic pain and chronic fatigue disorders**
4. **Neurological disorders** such as cerebral palsy, Alzheimer's disease, stroke, epilepsy, traumatic brain injuries
5. **Intellectual Disabilities:** Down syndrome is most well known
6. **Autism Spectrum Disorders:** Still difficult to categorize. Autism manifests in the first three years of life and persists through adulthood. Research suggests it is a neurological and developmental disorder. The diagnosis of Asperger syndrome no longer exists as a specific entity but is considered an autism spectrum disorder.

The above conditions just scratch the surface of non-apparent disabilities. Other examples can include heart disease, lung disease, hearing loss, multiple chemical sensitivities, cancers, asthma, and back injuries to name a few!

Disclosing details about disabilities or health conditions can be really hard when there's so much stigma associated with having a disability in general, creating the tendency of a person to feel like they are a less productive or valuable member of society. I think some men find it harder because they learned that the workplace is no place to admit to a weakness.

How Can We Be Allies to Those with Non-Apparent Disabilities?

Respect Privacy. Do not ask people about their disability or even why they need an accommodation unless they disclose to you first. Many are rightfully uncomfortable sharing their personal medical history or experience.

It's safe to assume that if someone has received a certain accommodation, they received it for a reason, but we can never assume what that reason is. It is important not to police people when they use these accommodations – or if they don't.

Pay Attention. Like any interaction with a stranger, we never know what a person is going through. Be thoughtful about how people interact with you. Especially pay attention to your

Non-Apparent Disabilities

September 25, 2022 *page 4*

language – erase “crazy, insane, blind, deaf, stupid, bipolar, retarded,” and phrases such as “they’re off their meds,” “I could kill myself,” or “they’re on the spectrum.” Our words can be hurtful and triggering.

Be a Friend First. Chances are we all know someone who is living with a chronic condition or disability. It’s not our job to diagnose, cure, or fix them.

At FRS, let the dialogue begin! We can create information sessions, quiet private space for groups who have self-disclosed social anxiety issues to meet, a scent-free zone, and a space to watch the service at church but in a quieter area, perhaps downstairs.

There is evidence that going to church, and that religion, religious training, spirituality, faith, prayer, and church-based social support are associated with reduced anxiety, and in many instances, depression is reduced as well. When I am anxious, I can’t stop thinking about my worry or problem and then I feel like I’m a failure and get depressed about it. I have had periods when I can’t break out of that cycle and after much inner work and encouragement from friends and family, I sought mental health support and medication with good results.

Remember the words of John O’Donohue: “One of the most beautiful gifts in the world is the gift of encouragement. When someone encourages you, that person helps you over a threshold you might otherwise not have crossed on your own.”

A few additional suggestions:

Find commonalities before thinking about differences

Don’t assume that a person sees their disability as a tragedy

If you suspect eye contact is causing discomfort, don’t insist

Ask if assistance is needed before providing it

Do not underestimate the abilities and talents of a person with a disability

Address the person, not their caregiver, and do not touch their mobility devices

Finally, forgive yourself in any mistakes you’ve made in social interactions. You have made a

mistake but look at what you have learned. It’s hard. I still think of my first year of teaching at the Cotting School when we still taught students to diagram sentences. I told a student to go to the blackboard and write the subject and predicate, but he was a little person, a dwarf, and without thinking I said, “just drag up a chair so you can reach it.” And he did! That was 55 years ago and I’m still trying to forgive myself!

I leave you with one of my favorite mantras, a blessing by John O’Donohue: “May you/I/we live this day compassionate of heart, clear in word, gracious in awareness, courageous in thought, generous in love.”