

Pastoral Care

Newsletter

For Member Care Committees,
Ministry and Counsel, Overseers,
and others who provide pastoral care
in unprogrammed Friends meetings

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Creating Access, Offering Hospitality, Sharing Gifts

Pastoral Care and People With Disabilities

by Sally Campbell

What is “The Spiritual Basis of Accessibility”? Ten years ago, in a paper of that title, my yearly meeting’s Committee on Disability Concerns wrote:

Accessibility is not only a matter of nuts and bolts, of ramps and bathrooms. It is also a question of our love and commitment to one another, and of our identity as a caring and a gathered people.

If this is true—and in my experience, it is—then questions of disability access are a pastoral care concern. Our work as pastoral caregivers involves helping the meeting understand and embrace specific Friends with disabilities, as well as fostering an environment that is as welcoming and accessible as possible to all.

I’m a “TAB,” a temporarily able-bodied person, and I’ve been involved for about a decade in efforts to improve access for Quakers with disabilities. In this article I hope to share some of what I’ve learned and how it might apply to your meeting, whether it is large or small, and whether it meets in a brand new or an ancient meetinghouse or in a Friend’s home. While this article focuses on physical and sensory disabilities, let’s keep in mind that mental illnesses, learning disabilities, and developmental disabilities raise similar, but perhaps not identical, challenges and opportunities in the meeting.

In keeping with the idea that people with disabilities can best speak for themselves, I asked some to share their thoughts. Here’s some of what I heard:

“Remember the disabled person is taking a big risk by coming to meeting, especially if she or he comes alone.”

“Make it clear that people with disabilities are not deficits, but in fact have particular gifts because they experience the world differently.”

“Money is a problem. Many disabled people have reduced income. I only have the stamina to work half time, for example.”

“I think maybe the most invisible aspect is the issue of fatigue—it’s tiring being in pain and all the little efforts one must make take their toll.”

“Probably most important is for Quakers to get involved in issues such as defending Medicaid and enforcing the Americans with Disabilities Act.”

“As the mother of a child with a disability, I truly believe that the most important thing is a caring, friendly attitude. My son might not be able to talk the way other kids can but he enjoys many of the things they do and he appreciates people coming over to say hello and including him in activities.”

A Caring, Friendly Attitude

On the journey to accessibility, many faith communities experience a shift in perspective. They no longer think only in terms of what they can do “for the handicapped,” but how they can enjoy ministries “with and by people with disabilities.” The Quaker belief that we all are ministers should make this



Sally Campbell

Taken at the Library for the Blind
by George A. Covington,
a legally blind photographer,
journalist, and advocate.

transition from condescension to full inclusion easier for us, as we seek to discover and share the unique gifts of ministry in our midst. New Friends need to know they are welcome to become full participants in the life of the meeting, and long-time Quakers who become disabled need to feel they are still seen as indispensable. Everyone wants to be seen as an individual who has gifts to share with the meeting.

For instance, I know a Quaker who has epilepsy. He carefully wrote out instructions for how to help him in the event of a seizure, and even acted out what to do. This was his idea, his gift to the meeting. As a result, people in his meeting were better educated about epilepsy in general, and knew how to respond correctly when he had a seizure during meeting.

Some people really cannot *do* much but they can be a part of the meeting. My mother in her later years had Alzheimer's and when she came with me to meeting many folks made it clear they loved her smile and her peaceful presence. That was her ministry.

Some people cannot be so peaceful, but because of their disabilities may cause disruption. Can the meeting find a way to understand this as an unexpected gift, something to shake the meeting out of its routine? Writing of people with mental disabilities, theologian Stanley Hauerwas says, "Exactly to the extent they create the unexpected, they remind us that the God we worship is not easily domesticated...[but is] a God that would rule this world not by coercion but through the unpredictability of love."

Finding ways to work together may not be smooth. Embarrassment at being seen as disabled may hold some people back from asking for help, so it is important for everybody in the meeting, especially pastoral caregivers, to be tactful and persistent in offering support. On the other hand the fear of being shut out can cause some people with disabilities to be urgent and insistent and thus to be seen as difficult. I've been amazed how often a seemingly impossible situation can be solved just by calm, friendly listening.

Remember, too, that many disabilities are progressive and transitions can be particularly hard. A little encouragement can help a person get over resistance to accepting the next stage. One year at the FGC Gathering, a man brought his walker and a large, attentive family, but it was not enough. He was exhausted on the first day and ready to go home. I was able to lend him a wheelchair. What a difference! His radiant smile was back. At the end of the week he confided that he had a wheelchair at home in the closet,

but he'd never used it. Now he was going to get it out and go to those art museums he'd been longing to visit.

This story reminds us that disability is hardly an "all or nothing" phenomenon. There may be people in your meeting with "invisible disabilities," such as some of the auto-immune disorders. There may be others who are deeply affected by their involvement in the day-to-day needs of a family member with disabilities. And then there is the fact that most of the "temporarily able-bodied" amongst us will experience temporary or permanent disabilities at some point during our lives.

Here are some other guidelines to carry in your mind and heart as you look for opportunities to strengthen your meeting's welcome and embrace:

- Everyone likes a genuine smile, a warm handshake, being called by name.
- Act the way you would with anyone. If you make a mistake say you're sorry and move on.
- Speak to the person with disabilities, not just to the TAB person who is with them.
- Be sensitive to the needs of caregivers and relatives.
- Be consistent. For example, if a Friend asks you to speak more loudly or slowly, don't trail off after the first few sentences.
- Show respect of personal space, including wheelchairs and guide dogs.
- Offer assistance, and then wait for acceptance. Ask how to help if you aren't sure. If refused, don't be offended.
- Remember that language changes over time, and that it's wise to use the words that the person with whom you are talking prefers to use. For example, one Friend may feel that "physically challenged" is an empowering and accurate term, while another may prefer the term "disabled." (On a humorous note, I remember that "Special Needs" at the FGC Gathering became "Access Resources" because one person who was then using a wheelchair said "What is so special about the need to use a bathroom?")
- Don't discount what someone says about the accommodations she or he needs.
- Don't make decisions about accommodations without consulting the people involved.
- Don't pretend to understand someone. Instead, ask them to repeat or reword what they said. You might ask them to spell or write if necessary.
- Don't raise your voice unless asked to.
- Don't deluge them with disability stories. They may want to talk about something else.

A Meeting Committed to Inclusion

Liberation and real access to the community will only be realized through personal relationships that develop into genuine friendships where shared vulnerability is the rule not the exception. —from *Copious Hosting: A Theology of Access for People with Disabilities*

As the saying goes, “attitudes are the real handicap.” Before we build a ramp or plug in a microphone, it might be wise to give the meeting a chance to ground itself in the experiences and feelings of the Friends who comprise it.

One way to start could be to have one or more worship-sharing sessions on disabilities and inclusion and exclusion, inviting each person to speak out of the silence from his or her own experience. From this process would grow an understanding of each other’s histories, hurts and hopes. Ideally, these sessions would take place before a particular person with a disability raised a particular accessibility concern. Queries and storytelling would be important parts of the process.

It is clear that these sessions could be painful at times. We need to recognize that much of our discomfort and awkwardness around disabilities is caused by fear. We are all awkward when new at something so we need to be tender with each other and ourselves. Non-disabled people fear feeling inadequate, being all thumbs (now there’s a disability!), or that their help will be rejected. They fear the unknown, the “other,” the messiness. At root, perhaps they fear becoming disabled, or they fear death itself. Some of the fears people with disabilities deal with are: of not being able to cope, of being dependent, of not being heard or taken seriously, and of being rejected. Even more troubling fears may emerge, such as being locked away, abused or killed.

Living in this society it is practically inevitable that we have unexamined prejudices, and worship sharing can give us a chance to examine them. We may discover an unconscious assumption that when people can’t do one thing, they can’t do anything: if he can’t walk, he is not intelligent, or if she doesn’t speak well, she also doesn’t hear well. We may have a vague sense that being disabled is something to be ashamed of, perhaps even a sign of God’s disfavor.

A story I might share in worship sharing is about a woman I know, a Quaker with both disabilities and a difficult personality. My meeting for years tried to treat her in as Friendly a way as possible. She had so many needs but we dutifully did our best. She eventually moved away and a few years later I saw her at a Quaker

A Basic Menu of Options to Increase Accessibility in Your Meeting

- Mobility:* Handrails, grab bars, a ramp, an elevator, uncrowded doorways and aisles, an accessible bathroom (really important), designated parking, doors that open easily, rides, help with groceries and meals, space for wheelchairs and scooters in the seating arrangement, access to rooms used for committee meetings and children’s programs—not just the worship space.
- Deaf:* Sign Language interpreter.
- Hard of Hearing:* Sound system, assistive listening devices, insist people speak clearly or use microphone, have a partner write what others say.
- Speech:* Have a partner read or interpret what they say.
- Sight:* Use larger font on computer, good lighting, recorded books or someone to read aloud, tell the person who you are and if you are leaving the room.
- Chemical sensitivity:* Good ventilation, choosing environmentally friendly cleaning products and fragrance free toiletries, respect individual’s needs.
- In general:* A room where people with disabilities can go, if they like, to deal with matters such as adjusting clothing, taking medication, or “messy eating.” Books in your library for all ages on the subject of disability. A line item in the budget for accommodations, from structural alterations to chemical-free cleaners.

When in doubt, ask what accommodations would be most helpful for a given individual. For example, not all deaf people can understand American Sign Language. Some people who use wheelchairs can drive cars and vans.

gathering. As we were walking along together, a three-year-old girl from her new meeting came running up to us, beaming with all the love in her heart and calling out the Friend’s name. In that moment I realized that I’d been missing something in all those years I was trying so hard. This woman was not a problem to be solved, a burden to be borne. She was a gift I’d been given, a person to be loved.

A Clearly Accessible Meeting Space

As the process unfolds, the meeting may choose to make major changes to the meetinghouse or, if it meets

in a rented space or a Friend's home, to seek a more accessible place to meet. (The January 2001 *Pastoral Care Newsletter* issue on the topic of "The Challenge and Opportunity of Meetinghouse Changes" addresses many of these issues.)

There are many choices to be made. In the process of choosing and accomplishing these changes, here are some principles to keep in mind.

Prioritize. You don't have to do it all at once. Encourage a patient search for a project which can be easily accomplished and will make a real difference. Once it has been done, celebrate and go on to the next accommodation.

Employ the concepts of universal design. What works for people with disabilities often benefits the whole group. For example, a ramped entry that welcomes the person in a wheelchair is often the most convenient for everyone. A highly legible sign will give a friendly welcome to all, regardless of ability to see.

Involve those with disabilities in all stages of the process. Not only does this acknowledge the expertise of the person with a disability, but the meeting will also be likely to get something that *works*.

Make it clear what you are doing or you may get into trouble. One person with a hearing loss has someone type the messages on a laptop. Her own meeting was used to this, but when she traveled to other Quaker gatherings people were initially shocked that anyone would be typing in meeting. Once they understood the reason, it was no problem.

As I picture it, a meeting on the journey to accessibility passes certain mileposts, including:

- Share attitudes, experiences, interests, needs.
- Appoint a committee including people with disabilities to carry this concern.
- Come to unity on commitment, time, energy, funds.
- Examine how your building's accessibility might be improved.
- Use resources such as those listed at the end of this article and others in your community.
- Publicize your accessibility at your front door, in your outreach, on your website.

Of course, few journeys that are worthwhile are linear. Just as your meeting accomplishes and begins to publicize one access improvement—say, the installation of an assistive listening system—it may find itself back at square one in regards to a new development, such as a child with disabilities becoming old enough for the children's program.

With Divine Assistance

As in marriage, this commitment to inclusion is likely to involve long, hard and tricky work, so letting God in to help us will make it go better. Pastoral care committees can remind people to take the time to rest amid the challenges and controversies and hear the Spirit calling us to become a loving community where all are welcome. Pausing to pray and ask for guidance whether individually, in small groups or in meeting as a whole, may help us to see a way where there seemed to be none.

In my experience working on access issues in Quaker settings, I've been frequently surprised by the timing of the gifts I received exactly when they were needed: a wheelchair, an expert ASL interpreter, an extra parking permit. I have become convinced that when the Bible says, "All things work together for good for those who love God" it is just stating an objective fact. ■

Sally Campbell is a member of Morningside Meeting in New York City and is on its Ministry and Counsel Committee. She is retired from the New York Public Library's Library for the Blind and Physically Handicapped. She was the Coordinator of Access Resources at FGC Gatherings from 1995-2002. Writing this article has encouraged her to begin working toward creating a Friends Access Resources Network.

Questions for Reflection

For individual consideration and/or worship sharing:

1. What have my experiences been with disability?
2. What can I offer to the meeting in its journey towards inclusiveness? What do I need?
3. Am I willing to slow down, to take the time to walk with, talk with, get to know and maybe even become fond of people with abilities different than mine, so that together we can face and deal with any difficulties that might keep us from becoming full partners in the meeting?

For meeting and/or committee discussion:

1. How can all of us together make our meeting a place where people of all types are welcome?
2. Is our meeting ready to boldly proclaim our desire to be inclusive and welcoming to everyone? Will we commit ourselves to give the time, energy, thought and funding necessary to making this a reality?

One Meeting's Experience

A Friend with Speech Impairments Gives Vocal Ministry

The Individual's Perspective: It is funny that I don't remember the first time I spoke in meeting. It was not too long after discovering Friends and first attending Claremont Meeting about 18 years ago. And although I did feel very much at home in the meeting, it was really a big deal. Yes, many people are nervous when they speak in meeting for the first time but, along with using a motorized wheelchair (I have cerebral palsy), my speech is severely impaired. It is fairly difficult to understand my speech; even those who know me well are stumped from time to time.

Fortunately, in addition to having a sense of humor, I am very patient and have a strong desire to be heard. A letter board and, later, a voice synthesizer* have also helped, although I don't have the dexterity to type out everything I want to say. Even so, speaking up in a silent meeting for worship was—and sometimes still is (especially in a larger gatherings, such as yearly meeting)—particularly daunting.

When I speak, I ask that what I'm saying be repeated. I have done this for years. This way, I know I am being understood and not just blathering away. I was very concerned that this process, which is often like a "what's-he-saying" game show, would shatter worship. I

* A letter board helps me communicate by pointing to letters arranged like a typewriter. A voice synthesizer "speaks" the sentences I type into it.

was also worried about who would do the repeating and if, in wanting to be understood, I was being egotistical, even un-Quakerly. Still, like others who find themselves rising in meeting, I couldn't keep quiet. As much easier as that would have been, I had to speak.

I talked about these concerns with several individuals in the meeting, as well as a committee or two. I was assured that, as with anyone, what I have to say is important and is worth the effort to hear. I was also told that, likewise, it is important for the meeting to learn to listen better.

Over the years, there has been a small and evolving group of Claremont Friends who repeat what I am saying in meeting. It has been a concern of mine that this responsibility, this burden, has been placed on them—they've also been asked to "translate" in one-to-one conversations—especially when I know that most people can "get" what I'm saying if they make the effort and don't have hearing problems. (Making sure that the hard-of-hearing hear the vocal ministry is also an ongoing concern in our meeting.)

This is a process in process. Far from disrupting the worship, however, Friends have told me how moved they are when they see this effort. It is a powerful example of and testimony to community.

—John Pixley, Claremont Meeting (Claremont, CA)

In Appreciation: Patricia McBee, Outgoing PCN Editor

Since 1996, *Pastoral Care Newsletter* has been edited by Pat McBee. About a year ago she announced plans to step down from that role, and agreed to serve on the editorial committee. This is our first issue since that transition.

It is appropriate that my earliest memory of Pat McBee is her voice on the telephone, since the major work of the *Pastoral Care Newsletter* is done on the phone. During the eight years that she edited the newsletter, we must have had close to a hundred phone conversations, usually shared with the other members of the working group which advises the editor. We valued her breadth of knowledge of Quakers and Quakerism, so helpful when we were looking for articles. Pat always sounds like a person ready to enthusiastically meet the next thing life has in store for her.

Another impression of Pat is her uncanny ability to see the point, no matter how well it is hidden in the forest of tangents and distractions. Some of us can talk around it endlessly—what the author was trying to say, how to tie up this loose end or that one—while Pat can find the nugget that is buried and focus us on that. Pat also can look at a whole mishmash of data, ideas, and experiences and see that if we change paragraph 4 and put it after paragraph 8 and use that for the introduction, after rewriting a few sentences slightly (but keeping the author's voice), things flow better to the natural conclusion which is now the first paragraph but clearly is better as an ending.

This short essay would be much better if Pat had edited it.

—Sue Heath, Clerk, Pastoral Care Newsletter editorial committee

One Meeting's Experience, continued

The Meeting's Perspective: Regarding faithful waiting and listening, our *Faith and Practice* says, "It may require one to rise and speak words that do not come easily, which may not be fully understood, or which may be uncomfortable. It may require action, or restraint of action, by some individual or the whole Meeting...."

John Pixley's cerebral palsy affects his entire body and he speaks with great difficulty. In the life of our meeting, the most important issues about John's speech arise regarding vocal ministry in meetings for worship.

When John first came to Claremont Meeting, we recognized the profound spirit of what he would bring to worship. He came to our committee to ask if he should minister vocally. Our response was that good order requires that he speak as moved during worship.

At first it worked out naturally that two or three people particularly adept in understanding John's speech "articulated" his vocal ministry by repeating what he said. Eventually, it became a matter for the meeting when no one with this gift happened to be present, and worship was seriously disrupted by too many people of goodwill offering a word or phrase.

With John's approval, ministry and counsel identified two adept people who were willing to be responsible for supporting John's vocal ministry in this way. We informed meeting for business of this arrangement, and made the request that others not "chime in" short of exceptional circumstances.

We all need to hold the meeting in the Light and not allow the work of articulation to displace worship. There are some in the meeting who feel their worship is disrupted by the time and effort required for John's ministry. One of the adept Friends has had to withdraw due to deafness. At this time no particular people are designated, but the meeting has remained attentive, trusting that when Spirit speaks through John, there will be one or two who are led to enable us to understand his ministry.

—*Aimée Elsbree and Charleen Krueger, past and present members of Claremont's Ministry and Counsel Committee.*

GROUPS & ONLINE RESOURCES

Addressing Hearing Loss Among Friends. www.quaker.org/fep/hearing.html

Deaf Friends Fellowship. (717) 687-3617 (Voice/TTY). aslfriends@mailstation.com

Friends Access Resource Network. www.FARN.org (under construction).

Friends Meeting House Fund. (215) 561-1700. Loans to make meetinghouses accessible.

The Lighthouse. (800) 829-0500 (voice) or (212) 821-9713 (TTY). www.lighthouse.org Resources for people with vision impairment.

Self-Help for Hard of Hearing People, Inc. (SHHH). (301) 657-2248 (voice) 301-657-2249 (TTY). www.shhh.org

Toxics Information Project. (401) 351-9193. www.toxicsinfo.org For people with chemical sensitivities and their allies.

United Spinal Association. (800) 807-0192. www.unitedspinal.org Free practical expertise to make buildings wheelchair accessible.

BOOKS

That All May Worship: An Interfaith Welcome to People with Disabilities, by Ginny Thornburgh and Ann Rose Davie. National Organization on Disability, Religion and Disability Program 2000. (202) 293-5960. www.nod.org.

Accessible Faith: A Technical Guide for Accessibility in Houses of Worship, by Elizabeth A Patterson and Neal A Vogel. Partners for Sacred Places 2003. (215) 567-3234. www.sacredspaces.org.

Copious Hosting: A Theology of Access for People with Disabilities, by Jennie Weiss Block. Continuum 2002.

The Disabled God, Toward a Liberatory Theology of Disability, by Nancy L. Eiesland and Rebecca Chopp. Abington Press 1994.

The Disability Rights Movement: From Charity to Confrontation, by Doris Zames Fleishcher and Frieda Zames. Temple University Press 2001.

Dispatches from the Front: Theological Engagements with the Secular, by Stanley Hauerwas. Duke University Press 1994.

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