

Disability & Community

Bellingham Unitarian Fellowship
Rev. Paul Beckel
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*My heart is moved by all that I cannot save:
So much has been destroyed
I have to cast my lot with those who,
age after age,
perversely, with no extraordinary power,
reconstitute the world.*

—Adrienne Rich (1978)

*Volumes are now written and spoken about the effect of the mind upon the
body. Much of it is true. But I wish a little more was thought of the effect
of the body on the mind.*

—Florence Nightingale (1859)

WELCOME

All who come in the spirit of goodwill are welcome here, no matter your age, race, class, gender identity, sexual orientation, or place of origin. We welcome you.

The following is from *Gates of Prayer*, the prayer book of Reform Judaism: “*Isaac asked the eternal: “Creator, when you made the light, You said in Your Torah that it was good; when you made the expanse of heaven and earth, You said that it was good; and of every herb You made, and every beast, You said that they were good; but when You made us in Your image, You did not say of us in Your Torah that humanity was good. Why, Lord?” And God answered: “Because you I have not yet perfected, because through the Torah you are to perfect yourselves, and to perfect the world. All other things are completed; they cannot grow. But humankind is not yet complete; you have yet to grow. Then I will call you good.”*”

Now what could *that* mean? Are we supposed to *perfect* ourselves? We come together seeking integrity, and wholeness. And we often sing about gathering here in one strong body. But aren't these ridiculously high aspirations? How can we become complete, strong, and whole when (at least for those over age 30) the years seem to be taking us in the other direction?

And this isn't just a wry complaint: deteriorating physical conditions can have an effect on our spirits: both the spirit of each individual, and the spirit of our human family.

So, given that we all have, or *will have* broken bodies, how shall our collective spirit be that of one strong body? Part of the answer, I believe, lies within the covenant that we have with each other. Will you say it with me? *Love is the spirit of this fellowship and service gives it life. Celebrating our diversity, and joined by a quest for truth, we work for peace, and honor all creation. This is our covenant.*

GATHERING SONG*Here We Have Gathered*

#360

CHILDREN'S FOCUS*Warren the Hearing Dog*

by Claydene Lederer

Warren comes to church regularly—along with Bert, for whom Warren “hears,” and Bert’s wife Claydene, who wrote this book, which is about how Warren was trained, and how he has changed Bert’s life for the better.

READING

In the Adventures of Huckleberry Finn, Huck and escaped-slave Jim are floating down the Mississippi together. They are wary of every sound they hear coming from the riverbanks, and don’t know one another very well yet. But after one long night of keeping watch, a tired Jim opens up a bit to Huck.

“What makes me feel so bad dis time ‘uz bekase I hear sumpn over yonder on de bank like a whack, er a slam, while ago, en it mine me er de time I treat my little ‘Lizabeth so ornery. She warn’t on’y ‘bout fo’ year ole, en she tuck de sk’yarlet fever, en had a powful rough spell; but she got well, en one day she was a-stannin’ aroun’, en I says to her, I says: “‘Shet de do’.”

“She never done it; jis’ stood dah, kiner smilin’ up at me. It make me mad; en I says agin, mighty loud, I says: “‘Doan’ you hear me? Shet de do’!” “She jis stood de same way, kiner smilin’ up. I was a-bilin’! I says: “‘I lay I make you mine!’ “En wid dat I fetch’ her a slap side de head dat sont her a-sprawlin’.

Den I went into de yuther room, en ‘uz gone ‘bout ten minutes; en when I come back dah was dat do’ a-stannin’ open yit, en dat chile stannin’ mos’ right in it, a-lookin’ down and mournin’, en de tears runnin’ down. My, but I wuz mad! I was a-gwyne for de chile, but jis’ den... ‘long come de wind en slam ...ker-blam!—en my lan’, de chile never move’!

My breff mos’ hop outer me; en I feel so—so—I doan’ know how I feel. I crope [around her, she just kep’ her head down en I crope ‘round ...] behine de chile, sof’ en still, en all uv a sudden I says pow! jis’ as loud as I could yell. She never budge!

Oh, Huck, I bust out a-cryin’ en grab her up in my arms, en say, ‘Oh, de po’ little thing! De Lord God Amighty fogive po’ ole Jim, kaze he never gwyne to fogive hissself as long’s he live!’ Oh, she was plumb deaf en dumb, Huck, plumb deaf en dumb—en I’d ben atreat’n her so!”

MUSICAL MEDITATION*The River*, written and performed by Linda Waterfall**MESSAGE**

The story from Huck Finn came to mind some years ago when I learned that my then three year old son Ben had a hearing loss. I feel incredibly blessed to have had the resources at the time for him to get testing, surgery, and follow-up care. Ben’s problem wasn’t severe. But it made me aware of how easily a *small physical* problem can escalate into a *complex of social* problems.

I’m grateful to Ben’s preschool teacher who pointed out that he might have a problem. My initial reaction was just like that of Mark Twain’s Jim—I doubted that there was anything physically wrong... he was just being a difficult, inattentive preschooler.

Testing proved me wrong. And ear tubes made an immediate and dramatic improvement not only to his hearing but in the way he interacted with both friends and family. I had thought that irritability and aloofness were simply part of his personality. I'm so glad that my continued *expectation* of this didn't lead to these becoming permanent character traits.

Over the next year, the hearing loss returned, and once again I didn't notice, or didn't understand. A few weeks before he got ear tubes for a second time, he was participating in a dance class recital, to which all the parents had been invited. Ben loved this class; it was thoughtfully designed to enable four year olds to coordinate their emerging physical, intellectual, and auditory skills (integrating body, mind, and ear). They learned to listen carefully and to respond to rhythms, tones, and contrasts by moving their bodies to musical cues—both independently and as a group, and with feeling.

Watching their winter recital, I had been completely impressed with my child and amazed that his instructor had these kids responsive, in synch, and very expressive. (And non-self-conscious—that's such a wonderful thing about 4 year olds!) When we joined the class, his hearing had been "fixed," so it didn't occur to me to tell his instructor about the problem, which crept back very gradually. Then at the spring dance recital, I saw Ben looking somewhat dazed and confused. He didn't follow spoken instructions. He looked to the other kids for *visual* cues of what to do next. He responded to everything more slowly than he should have, but fast enough to *mask* the fact that he couldn't hear well.

As a proud parent, I was worried that he appeared awkward, and stupid. Since he also happened to wear an eye patch in those days, I could just imagine the other parents pitying the slow kid out there.

The other parents probably never took their eyes off their own darlings and didn't give the slow kid a second thought. But that day I was keenly aware that there must be both children and adults all around me who have disabilities that I have no clue about.

The first irony is that all this happened in a program explicitly designed to teach listening skills (the class was focused on being in touch with one's environment and responding to it...the dance part was just a lure and tangible reason to ask them to pay attention). Another irony is that both the ear tubes, and eye patches, came into Ben's life the same year that he entered a preschool program in which classrooms were set up with both special-needs kids (with significant physical, sensory, and developmental disabilities) and typically-developing kids. It was called the Integrated Program, and they gave the "typically-developing" 4-year-olds grandiose label of "peer models"—maybe as a subtle incentive to get parents of the "normal" kids to enroll. They also made it free for the "typically developing" kids, and made it even more attractive with an extraordinarily high teacher-student ratio.

Fortunately the teachers were under no illusion that "peer model" was supposed to mean "flawless." On the contrary, Jane and I learned that it's not unusual for the "typically developing" kids to have problems like Ben's identified during the year. Because the teachers cared, and knew what to look for, and paid attention.

How we encounter disabilities in ourselves and in others can tell us a great deal about where we are on our spiritual journeys.

You may periodically hear the voice of John Hockenberry, a reporter on NPR. What you don't hear in his voice is the fact that he is paraplegic. In his memoir, Hockenberry writes about the auto accident that crushed his spinal cord at age 19. He says: "The most powerful sensation I have ever felt is of no sensation at all." He wasn't talking about God, and yet he describes this moment in almost reverential tones.

Prophets of every era have called upon us to find God in brokenness, weakness, and vulnerability. Instead we usually run from brokenness, weakness, and vulnerability...if we can.

UU minister Victor Carpenter, whose companions on the spiritual journey have included two disabled daughters, writes 'grace rarely comes as a gentle invitation, but more often as an assault from which we would prefer to flee...'

Maybe it's natural to want to flee from distressing situations that are hard to understand. And maybe it's also natural to be morbidly curious. John Hockenberry notes with amazement that strangers will walk up to him and ask very personal questions.

"Once a flight attendant noted how adept I seemed to be in getting on planes.... "You really don't let anything stop you, do you?" - I travel a lot, he replies.

"I guess you're the first handicapped person I have ever seen up close. Have you ever thought of killing yourself?" I wondered if this question appeared in the official training manual under 'Handicapped Patrons: Suggested Conversation Starters. [I responded:] "Do you ask lots of people on your airline if they think of suicide?"

"O goodness no, that would be crazy. I was just wondering about you because you get around so well that you must have really done a lot of praying to get this great attitude." My great attitude was eroding fast.

[She continued] "Can you, I mean, can your body, I mean are you able to do it with a woman?"

This line did not sound like one from the manual....

Unitarian Universalists hold high the principle of justice, and we seek to create *fair, win-win* situations. But we also have a great deal of tolerance for ambiguity, and so, at our best, we can also face an unfair, *no-win* situation, without needing to pretend that it is something different than it is.

Disability is fraught with senselessness. From "Why did this happen?" to "Why did I deserve this?" For example, Hockenberry writes of the bizarre hierarchy of spinal cord injury patients. He notes how the best wheelchairs and services go to people like him whose bills are paid by auto insurance companies—whether the accident was caused by a drunk stranger or a drunk self,

he says, these people get the best. Lower on the scale of benefits are disabled veterans. On the bottom rung are those *born* with a degenerative illness who receive only public assistance. Not that any other hierarchy would make more sense, but this is emblematic of the senseless world of disability.

In the ancient tale, Sisyphus is condemned to eternally roll a boulder to the top of a mountain, where it rolls right back down, and he has to start over. What more dreadful punishment could there be, the gods thought, than hopeless effort. For a gerbil, it may be no big deal to tread life away like this, but the tragedy of Sisyphus is that he is fully aware of the hopelessness of his situation.

When we face disability in others or ourselves (and we should all be fully aware that for ourselves it's just a matter of time) ...When we face disability in other or ourselves, we often try to make *sense* out of the situation. Why did it happen? What will happen next? We ask these questions, even when there is really no answer possible. Then, eventually, it may become apparent that, on a physical level, *nothing* is going to improve. And a terribly painful paradox arises: how can I transform a situation that will not change?

And yet time and again people do find ways to change a situation, change their response, change their awareness, and change their communities.

A mother in a family coping with her husband's very slow demise from Lou Gehrig's disease identified these among the hard lessons that she had learned:

- that she must stop expecting rational explanations for the unexplainable;
- to let go of trying to control the uncontrollable;
- [to ask for help];
- and to witness the suffering of another by staying present and doing only what is possible.
[from Pauline Boss, *Ambiguous Loss*]

Alice Walker put it this way: "Plan, but don't plan as if it will all happen as you planned it...expect nothing and live frugally on surprise."

Such forward-looking—in a situation that disallows certain forms of hope—such forward looking is appropriate for all of us, in our wide range of disabled, and not-quite-yet-disabled, conditions. It's important for families, and caregivers, and members of a larger community in which disability is increasingly present.

People often go to church looking for miracles or praying for circumstances to change. Some who come here may be disappointed when our prayers tend to be like the one of Indian poet Rabindranath Tagore (in our hymnal), a prayer which reads:

*May I not be sheltered from dangers but may I be fearless in facing them.
Let me not beg for the stilling of my pain, but for the heart to conquer it.
Let me not crave in anxious fear to be saved, but hope for the patience to win my freedom.*

Grant me that I may not be a coward, feeling your mercy in my success alone; but let me find the grasp of your hand in my failure.

Maybe it's easier for me to say stuff like this because neither I nor anyone in my immediate family struggles each day with serious disability. I suspect that when it happens to me I will probably cry out with anger and possibly despair. I will ask why me? why now? ...maybe even plead for relief... even if I have no confidence that there is anyone, anywhere, who could make that happen.

As a not-yet-disabled person, I can only hope that from moment to moment I can appreciate and accept myself as I am, and come to terms with the dehumanizing ignorance naturally present in myself and others.

And though I don't believe in a God who would intervene to change things for my private benefit, I do believe in miracles. I do believe that people can change. What we do in church would be pointless if we didn't believe that people can change.

I believe that we can move from despair to hope. We can move from fear to generosity. We can move from isolation to belonging. We can move from bitterness to gratitude.

In all of our various stages of disability or not quite yet disability, we can begin to remove barriers for others. We can remove barriers to action. We can remove the barriers in our attitude. We can remove barriers to communication. We can remove the barriers of neglect or avoidance.

By facing the pain—in ourselves and others—we might gain access—to something deeper. Let us fight then for access-ability here in this fellowship, here in our community, and here (heart) as well. Amen.

SHARING OUR GIFTS

Your generosity makes possible this community which strives to be accessible to all.

SENDING SONG *Lean on Me* #1021

BENEDICTION #505

Let us be at peace with our bodies and our minds. Let us return to ourselves and become wholly ourselves. Let us be aware of the source of being, common to us all and to all living things. Evoking the presence of the Great Compassion, let us fill our hearts with our own compassion—towards ourselves and towards all living beings. Let us pray that we ourselves cease to be the cause of suffering to each other. With humility, with awareness of the existence of life, and of the sufferings that are going on around us, let us practice the establishment of peace in our hearts and on earth. Amen. —Thich Nhat Hanh