



## Known in Another Way

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I want us to know our community in another way. I want all of us to be known in another way, where we are people first and conditions second. I want us to demonstrate radical hospitality on a daily basis. I want a lot. I have rarely come across a sermon topic where I learned so much and felt so personally moved to make a change. Leadership consultant and community leader Peter Block writes

When we believe that the ‘other’ is the problem and that transformation is required of them and not of us . . . and until they change, we need to stay distant and contain them. This diverts us from the realization that we have the means, the tools, the thinking to create a world we want to inhabit, and to do it for all. If we saw others as another aspect of ourselves we would welcome them into our midst. We would let them know that they belong, that they are neighbors, with all their complexity.

Block’s message is true for anyone seen as “other,” whether that is someone who is poor, who has served time in prison, or is an immigrants. For this morning, let us envision a world where we, those of us who do not consider ourselves to be living with disabilities, need to understand and accommodate people living with disabilities. The gift of this understanding and accommodation is a deeper understand and compassion for ourselves. It is not patronage or pity. It is awareness and acceptance of the complexity of the human experience.

When I chose to preach a sermon on disability I didn’t really know what I was getting into. The irony is that I have worked as a personal care attendant for two people with disabilities. They taught me a lot. In college one of my dearest friends used a wheelchair (again I learned a lot), and I worked for a disability advocacy group entitled “Abilities Unlimited.” As an adult I was disabled by chronic back pain for several years, even to the point of needing to take a short term disability leave from ministry. I did consider myself disabled at that time and I learned a lot from the experience. And still there was so much I had not considered until I sat down and chose to listen again to the experiences of people living with disabilities.

I was also unaware of the variety of conditions that can be considered disabilities. A few weeks ago a woman from a local service agency came by to see about renting some space in our building. Her agency works with individuals with disabilities. She told me that her agency serves anyone with a physical, cognitive, mental, or sensory condition that affects their way of living. This includes individuals with severe depression, anxiety, and paranoid schizophrenia.

A member here wrote to me

From what I am learning, mental health and learning disability struggles often co-exist. ADD/HD, anxiety, OCD (Obsessive Compulsive Disorder), and severe dyslexia seem to be the bundle in our family. In my family or origin, I am the fortunate “black sheep” that had no trouble learning to read. My dad, brother, uncles, cousins, and children have had severe struggles learning to read or write. It has probably contributed to the high rate of high school dropouts and homelessness in my extended family . . . every day more and more is being figured out about learning disabilities and I hope by the time my kids have kids, the mainstream will find effective ways to teach reading and writing that takes into consideration the spectrum of learning differences.

Echoing this sentiment and the words of Peter Block someone else wrote to me

Today, I still don't like to tell people I have a learning disability. Even to this day, when I do tell people this tid bit of information, I believe people think I am stupid. So instead of saying, “I have a learning disability,” I like to say, “I think differently than other people.” And if you were to ask me what MY definition of a learning disability is, it would be that – a different way of thinking and learning. I don't view the world in words. I view the world in pictures.

What would we gain as a society by harnessing the power of people who view the world in pictures and other ways?

A number of you wrote to me about your struggles with ADD or ADHD. We regularly hear about children who are living with ADD or ADHD. I was interested to learn what happens when children with this condition become adults. One person wrote to me about ADHD and marriage

Attention Deficit Hyperactivity Disorder (ADHD) is in short, easily distractible and high energy. It is the easily distractible part that is hardest for me. My husband is easily distractible and there are aspects of this that are hard for me . . . punctuality is not a factor for my husband . . . then there is the fact that his distractibility prevents him from doing chores. The last time we did a chore list he followed it for a week and then forgot about it. Now that our baby is here I feel like I do everything.

Another person spoke to me about her experiences with ADD. I would never have guessed that this person lives with ADD because I have worked with her and found her very organized. But she explained to me

Everything leaps out at me – patterns on the floor, what is on the walls, it keeps me from concentrating and being coherent. People see me as normal, whatever that means. And I battle every day to get things done and it is exhausting. When a disability is not apparent it is hard. It is a “hidden disability” and I need to hide it even more. I am not missing a hand. Maybe this is all in my head. This is something I should be ashamed of. I should be able to control this, but I can’t.

A number of you wrote to me about your “strange” feelings of shame and self-doubt, both people with “hidden disabilities” and those with obvious physical conditions. One woman with epilepsy told me that people look at her like she is stupid because she is an adult and she doesn’t drive, but her epilepsy has not yet been contained well enough for her to drive. She would like to get a reduced fee bus pass because of her disability, but epilepsy does not “count” for a reduced fee disability. How ridiculous is that? We do have the means and the tools to amend this.

I also remember the shame of chronic back pain. I too was someone who appeared perfectly healthy, and relatively young. I was in my mid 30’s at the time. Yet, I could not sit in soft chairs, or lift a skillet weighing more than 3 lbs. and I could not open heavy doors, and most public doors are really heavy. I would come to a door, and apologetically ask someone to open it for me. I felt such shame and humiliation, not only for the need to ask for help, but because I looked completely healthy.

Peter Block explains that we push people who appear to be “other” away because we are afraid we are vulnerable and that we are them. He is right. But why is it shameful to need some help with a door, reading, or driving? Logically, why is this shameful? There is no logical reason. It is not about logic, but about emotions of fear and shame.

And again this is why we must be more welcoming and hospitable to people with disabilities, because most of us have some sort of a disability, or had some sort of a disability, or will have some sort of a disability in the future. In our fear, we are denying our humanity and the human condition, and wasting opportunities to learn how to serve the whole society better. Even if you have not yet had a disability, as you age there is an excellent chance that as a human you will experience visual, cognitive, or auditory impairment, pain, and mobility issues.

A member who has a child with a disability reminded me that not too long ago, children born with obvious disabilities were sent to institutions, where they often lived shorter lives due to lack of knowledge and adequate care. One of you sent me a story about a couple who gave birth to a child with spina bifida (spinal column is not closed) in 1952. This couple was told “you can’t care for this child,” and “don’t bond.” The stricken couple did as they were told, mourned in silence, and sixty years later had not recovered from the grief of their separation from their baby and her death in an institution before she reached the age of one.

Sixty years later, infants with spina bifida are treated much differently (the area is immediately closed). My dear friend from college has spina bifida, so it is condition I know about. I was dismayed to realize that if my friend had been born 15 years earlier she might

have died from medical and emotional ignorance and neglect. This fear and the subsequent sense of secrecy and shame is still with us.

People with disabilities bear the burden of our societal fear and shame. One member sent me excerpts from a blog written by a woman she knows. The woman writes

Today, as my MS (multiple sclerosis) symptoms progress, I am reminded of the humiliation I felt as an uncoordinated child. In my adult life before MS, I prided myself on my independence and on my ability to make my way in the world with little material or physical assistance. I had outgrown my constant awareness of my body and the space it occupied. I felt independent and even at times somewhat graceful – and I loved that feeling. However, because MS has brought with it a growing dependence and gracelessness, I have lost much of the physical and emotional confidence I spent most of my adulthood working to develop; as a result, I have begun to isolate myself more and more. I am hesitant to attend social events at which I will be forced to navigate my chair through crowds of people I do not know; when I do go out I am inclined to apologize to everyone I see for the “extra” space I occupy. The humiliation I feel about occupying more space than I did when I was able-bodied is eclipsed only by the humiliation I feel about my inability to “rise above” by disability, to “emerge victorious” over the disease. Before MS began gnawing at my ability to function “normally” in the world, I was blissfully unaware that people with chronic diseases are constantly humiliated by the message that we should do “battle” with our diseases and spend every ounce of our waning energy resisting the physical and cognitive impairments that visit us. Media segments about chronic illness feature stories about disabled heroes who overcome the ravages of their disease to climb mountains, run marathons, or accomplish other extraordinary feats. Celebrity physicians make sweeping claims about how exercise and strict dietary or pharmaceutical regimes will transform our disease into manageable conditions.” What these claims ignore is that most chronic illnesses like MS take varying forms and that exercise, diet, and pharmaceutical regimes are “hit and miss” in terms of success for any given individual. Nonetheless, media doctors’ overblown and inaccurate claims shape attitudes about the level of control we have over our symptoms, often leaving those of us whose progression continues unabated to wonder what we are “doing wrong.”

I remember quite well the guilt and self-doubt I felt when I lived with chronic back pain. It was years before the condition eased up, though it has never, and will never completely go away. I also expect it to return someday, mostly because I am not certain why it was so bad in the first place or exactly how it improved over time. I was not and am not in control of my back. The times I most desperately wanted to “rise above” left me crying tears of frustration, pain, and despair. We live in a ridiculous self-denying myth about the soft vulnerabilities of our minds and bodies. How can we learn to love our vulnerabilities and those of our neighbors? And when will we stop judging and reprimanding ourselves and others when we have disabilities that require a different level of time, education, attention, or space. Our minds and bodies are diverse. That is our human story.

There are some disabilities that are deeply challenging for the people who have them and those who work with and love them. One of you wrote to me about your work as a speech teacher, a job that is a great joy in your life.

I rarely feel sad for the children I work with because of their disability. The exception may be children with autism. I have never experienced such a roller coaster ride. No other classroom has made me cry so often, sometimes out of frustration, but just as often with joy. With these children, even the smallest changes can be a triumph that bring me to tears, and I am just as often brought to tears out of my own inadequacy to help them communicate. Last week, I was brought to tears when a seven year old girl with very little functional communication said “I want bubbles,” and the week before that tears were in my eyes when an eight year old boy had a hold of my hair and was pulling and wouldn’t let go. It did not hurt, but he was so frustrated that he was grabbing and pulling at my hair and clothes, and he could not communicate what was wrong. I didn’t know what he needed and I couldn’t help him communicate it. . . I just thought “I know you are trying to tell me something, but I don’t know what, and I don’t know how to help you.”

A parent wrote to me

Our most disabled child has a personality disorder. There is no medication for it. That is who he is. Intolerable things happened when he was young. He dominated family life. He bit the other children, tried to strangle a sibling, punched a child at school. It was a very difficult family life. That is who he is. What do you do? As an adult he now lives in poverty, has an addiction, and is virtually unemployable

Another parent wrote to me and said

My step-son is disabled but very high functioning. It has been a long struggle with mental and social challenges. In school he had a difficult time making friends and related more to adults. His future pains me daily. Mostly I wish he had friends.

But on the other hand, people with disabilities are people first. One woman told me that she can’t remember all her disabilities. That she would have to look them up. She told me that she was diagnosed as a young child but that she doesn’t feel like she has a disability. Today she works with adults with disabilities and explained to me “Most clients can do a lot. Some just need assistance.”

We all just need assistance. The film *Certain Proof*, about three children with cerebral palsy has this tag line, “but the biggest disability is our inability to see behind it.” “It” being the disability. Our societal perception is what is truly disabled. As someone told me in frustration, a person with a cognitive disability still has a mind. A person who is paralyzed still has a body.

What you can do today is change your language (if you haven’t already). We don’t say “retarded,” we say “cognitive disability.” We don’t say “handicapped,” we say “disabled.” People have disabilities. They are not “disabled people.” People are first. Conditions are second. I know it takes an extra minute to remember that, but it is worth it. Our language

alters perception. Let's demonstrate radical hospitality and know one another as people, first and always. People are diverse. People are beautiful. Go enjoy your beauty and that of others.