

Speaking for Myself: Reflections on “Passing” and Labels, 2002  
Ruthie-Marie Beckwith, Ph.D.

**Abstract:** Poverty is viewed as one of the major contributors to stigma in this personal essay on labeling and its impact on people’s humanity. Mental illness, a disability with no visibly apparent indicators, is particularly explored from the author’s own experience in searching for recovery. Working toward empowerment for oneself and others is presented as a solution to overcoming cultural barriers.

**Key Words:** Stigma, Mental Health, Recovery

The Opryland Direct Action Prose Poem, 1993

Sitting in the minimum secure facility with fifty women—all of whom have disabilities. We have been arrested for standing in the driveway. Doesn’t seem all that much like civil disobedience but it qualifies for criminal trespassing. “Anne” tells her story to a woman next to her. Both in wheelchairs, they share their histories. “Able-bodied” me eavesdrops—I am not included in their worldview now.

“Anne” tells the story of her brother threatening her with a gun when she screamed for help to get off the commode. As she described telling him to just go ahead and shoot, I flashback to the front yard where my mother aimed a shotgun at my stepfather who was standing directly behind me. “Anne” and I were both in the way. She found a way to claim her personal power. I am transformed into a deer, my eyes locked on the gun, forever frozen in time.<sup>1</sup>

It’s late at night and I’m up pondering how it is that I could possibly have something in common with Franklin D. Roosevelt, a national legend, highly regarded, and much revered figure in the world of disability. It’s there though; just one tiny similarity except mine isn’t taking a national debate to bring out into the open. He “passed” on being seen as a person who used a wheelchair and I, until very recently, “passed” on letting people outside of my closest friends and colleagues know I have mental health labels.

Thoughts and feelings about being labeled and being the labeler continue to abound. Characters on a recent television episode of the American TV show *CSI (Crime Scene Investigation)* even talked about the difference between having a visible disability and an invisible disability. A glorious new publication by *Self Advocates Becoming Empowered*<sup>ii</sup> (2002), *Sticks ‘n’ Stones*, gives voice to the feelings of the labeled people whose movement was launched on this very debate. Other segments of the disability rights movement insist on using a label as a way of proclaiming their identity and framing their own cultural experience. Some professionals and family members have never abandoned the old labels for the new nor accepted *People First*<sup>iii</sup> language proscriptions while others disparage the whole enterprise. Still others condemn the whole *People First* language effort as language tyranny being carried out on by an out of control societal wave of mandating what’s “politically correct.”

In my life as an advocate during the last 20 years, I respected and carried out the mandate of the statement issued by some folks long ago in Oregon by *People First International*: “We believe labels hurt people...” You all know the yellow poster, “Label Jars, Not People”? In 1994, I testified under oath at a deposition that I couldn’t and wouldn’t label the people I worked for even though I had the credentials that the attorney for the *Voice of the Retarded* thought were satisfactory to meet his demand to do so.

However, in all of the time that I campaigned actively against the process of labeling people, I was also campaigning heavily against the demons of a past that ended with a few more letters being added after my name: PTSD<sup>iv</sup>, DD-NOS<sup>v</sup>, along with the words, depression, anxiety, and one which strikes terror into the heart of any good behaviorist, SIB<sup>vi</sup>. At the same time, the campaign against those demons gave me “Other Professional and Volunteer Experiences” to add to my resume like, “Being an advocate on a locked in-patient unit for someone dumped into seclusion for 24 hours while you’re an in-patient yourself” and “Criminal justice work on the inside while serving five days for DWD (Driving While Disassociated)”.

For a number of reasons, I never brought these personal experiences to the table as examples when I worked as a “professional” advocate and sought to empower others to speak for themselves. I saw myself then as almost a tool that the people I served had at hand to open themselves up, connect with others, use as a guide and then springboard from as the leaders and owners of *their* movement. I, as the “advisor,” was seen as at-one-with, but not “of” their movement. And, because I was cast in that role, I never felt like I was free to share/explore any other identity, as others who had disabilities but were leaders within the disability rights movement were able to do. Finally, as I continued to serve in the role of the “advisor,” I couldn’t help wondering, on a personal level, what life’s little quirk had led me to blunder into being an organizer for and of a movement in which I would never feel comfortable disclosing who and how I came to be the person I am.

### Going it Alone vs. Going it Together

Yesterday, here in Nashville, Bobby Silverstein was the wonderful keynote speaker at our annual State Independent Living Council Conference. He shared the admonishment that Justin Dart had given him regarding his role in the disability rights movement after he had stepped down from his work with the Senate Sub-committee on Disability Policy: Teach. Justin gave me a similar missive when I left *People First of Tennessee, Inc.: Organize*. Continue to organize but with a different focus. He told me to put my organizing expertise to use with people who have mental illness, confident I guess that I would somehow figure out how to get in the door.

Herein lies the heart of my midnight dilemma—Justin’s missive and the very real fact that in reaching out to the mental health consumers’ movement, I feel I have found a place where for the first time in my life I can truly be myself with all of my bumps, and warts, and scars hanging out there for all to see. At *Our Place*, our local mental health drop-in center, there was some initial confusion when I landed on their doorstep, but I was readily accepted into the fold. Acceptance is a heady thing. Of course, I was labeled “high functioning” because I “pass” so well and as such, given work to do. I grimaced at the “high functioning” remark and accepted the work.

At the time I appeared at *Our Place’s* doorstep I was: supporting myself with consulting projects, a divorced single parent of three, facing breast surgery, and learning to accept that lightning can indeed strike a person more than once. I was also taking enough drugs to admirably hold my own in any pharmaceutical conversation with the other mental health consumers who struggled to be there on a daily basis. The work I was given and accepted was teaching consumer education (B.R.I.D.G.E.S.)<sup>vii</sup> classes once a week. That, and the sense of real personal empowerment I felt at being a valued member of a consumer run organization, became one of the primary recovery vehicles that carried me back to the main road of the disability community’s struggles.

So here I am facing the biggest irony and conundrum of my personal/professional life: the ticket into the mental health consumer (c/s/x/r)<sup>viii</sup> movement means taking up the mantle of being a labeled person. I know I am not alone. I've spoken with friends who are struggling with the prospects of "crossing over," of "coming out," of "being yourself." We've talked about the constraints we've felt in the past and why we haven't done it until now. We've talked about our "cognitive dissonance" with the whole labeling thing.

Another theme we've explored is how readily we're accepted by other mental health consumers as legitimate spokespersons in our own right on our word alone, but rejected as such by some of our fellow colleagues in the disability rights movements, some of whom we've worked with for over half our lives. We've talked about how we have worked so closely with people across the disability community and yet we cannot, in this community, find a home of our own. We've talked about how the plurality of our various roles we've played over the course of our "careers" seems to be denying us the opportunity to have what could be the most plausible role of all: serving as bridges between and among all of our various factions and fictions.

For me, what it seems to come down to is that because I have done such a good job of "passing," few accept I am eligible to bear the mantle of being a labeled person. It's true that I have not faced the public denigration and stigma of being forced to carry a mental illness label outside of trying to get in-patient services from recalcitrant insurance companies and avoid incarceration. My denigration and oppression was primarily private and I've spent many angry years and dollars dealing with that legacy. Yet, my current experience seems to tell me that this lack of public service as a publicly labeled person is somehow a key factor in the admission criteria.

The campaigns against my demons were shared only with closest friends and family until now. I, like FDR, had that choice. I'm grateful that I was able to keep my campaign private because it afforded me sorely needed and highly cherished energy, even though many perceive me to be a somewhat overactive-type person (another form of "passing"). The energy I was able to carefully garner was put to use in staying alive and developing the coping mechanisms I needed to fend off the demons, the side effects, the after effects, and the on-going fallout that physical, sexual, and emotional abuse leaves in its wake. Plainly put, I was able to divert the energy I gained from not having to fight the fallout that comes with being a publicly stigmatized and oppressed person in our society to helping to fight the oppression of others.

### My Own Big Picture of Our Real Division

As an advocate/c/s/x/r/whatever whose most visible work has been within the "developmental disabilities" community, I fret a great deal about the inequity of the separate and disparate support systems that continue to be promoted for us, by others, and amongst ourselves. Whenever I make the time I need to go to the mental health drop-in center to get "centered," I sit and wonder about a lot of things that usually have nothing to do with my own recovery. I've met a lot of wonderful people there and admire their resilience at dealing their own human needs and aspirations in a society that de-values and seems increasingly willing to toss some people away. I reflect on the amazing wisdom of having 50 or so mental health consumers control one aspect of their own destiny and recovery with the amount of money that would currently only cover the cost of keeping one person in Tennessee in a state-run ICF/MR for less than three months.

In my fretting, my stream of consciousness invariably bring me back to what I believe to be the most divisive element within the disability community even more so than things than like

who/what system(s) are for and how they carry out their work; poverty. It is poverty that frequently decides who among us gets labeled. Poverty typically dictates where we will fall within our own disability caste system. It dictates whether someone will have the opportunity to speak for themselves and whether their wishes and decisions will be respected and honored. Finally, poverty factors into who will be anointed to speak for us and ultimately, whether they will choose to be accountable to us.

Most experts agree that poverty leaves its own lifelong stamp on one's soul that is hard to erase. Growing up with a single mother of seven children who was in denial about her own mental illness meant that I spent a lot of up close and personal time with poverty. I also spent some time voluntarily poor due to some good decisions as well as some bad.

Inasmuch as I've waded into a new personal era of being more personally "open and sharing," I've also spent some time talking with close friends and colleagues who shared the experience of poverty at one point or another in their lives. We acknowledge readily that we didn't transform ourselves into solid middle class citizens on our own. Along each step of our journey we had people who lent a hand, a dollar, a shoulder, and a real connection to reach out to. However, each of us acknowledges that we continue to look over our shoulders for reasons the experts don't typically describe or suspect. Many of us who were assisted in rising up out of poverty by others don't look over our shoulders for fear that poverty will again overtake us. We look over our shoulders for another reason entirely: a sense of social reciprocity.

### The Challenge: Walking the Walk with No Roadmap

I find myself now walking a walk with no roadmap in hand. In reinventing myself and launching myself into another career cycle, I've decided that an integral part of who I am can no longer be left behind at the door. In the process, I am struggling to integrate what I've learned from moving toward healing myself to approaches that could be taken toward healing the way I do work in collaboration with others.

Burton Blatt, a man who was deservedly revered, warned us in 1981<sup>ix</sup> about the "bureaucratization" of the values that we seek to promote and embrace in the work we do. His effort to sound the alarm about the impact of the advancing march of rules and regulations as an effort to keep people safe, and the programs that served them humane, was like most of the things Burt did--prophetic. Burt's prophecies have played out as he foresaw—rules and regulations were developed to codify such things as normalization, social role valorization, and mainstreaming, and continue to be developed for other "best practices" that have emerged since. Quality assurance efforts continue to try to get at and transform into a checklist those values that define how people with disabilities, families and many practitioners wanted people with disabilities to be treated. However, like Burt predicted, they will never be a substitute for walking the walk.

I continue to steadfastly believe that it is down in the "roots" where the mystical seeds of social transformation are nurtured and planted. Moreover, I continue to believe that social movements are not an artifact of the "sixties." People have been joining together to change their social condition for thousands of years. Following the bubonic plague in the 13<sup>th</sup> century, the serfs who survived banded together to take advantage of the depleted labor force to become "freemen!" Unknowingly, they helped to create the map that led to the Renaissance and its legacy of our current euro-cultural context.

With no map in hand, it is very hard to find and get to places where the practice of social change itself is being transformed. It seems almost serendipitous when I encounter other people who are wandering around with no map in hand as well. I instantly want to install a sign-post and am easily distracted with the self-assumed responsibility of being a cartographer and reporter rather than letting myself just enjoy the landscape. Even so, I also find myself frequently slipping the old map out my pocket and wishing that a new print run rather than a major new expedition would serve to help us all move forward.

Like all who work at recovery, questions and situations that challenge my resolve to be different and do things differently lay around every corner. Our codified values and quality assurance checklists have not brought us collective equality, justice, or liberation. The sirens of our individualistic culture lure us to the rocks of separateness and isolation. The current ways of confronting the abuse(s) of power (personal and systemic) are rearticulated and reinforced as the only approach that those who are in need of confrontation can understand. I sit in my little home office and can't help wondering, "How do we know this to be true and what will we stand to both gain and lose if we try another way?"

#### Endnote and Invitation

Collective thought and action by a group of people who seek to transform the manner in which their specific and unique needs and interests both serve and support society does require some form of an accepted identity, at least initially. This brings me back to the issues of labeling and "passing". Perhaps an additional mystical seed needs to be planted in the interest of transforming our organizational practice. Although the recognition and acceptance or rejection of one's own labeled identity used to be central to the beginning of the process of liberation, maybe on the new road map anyone who walks the walk of sharing his or her own personal authenticity has equal legitimacy.

A process based on respect, I think would be as good as any place to start. But more so, I believe we must build a collective process in which we all listen to one another and all voices that seek to help us restore and reclaim our humanity are welcome. In such a place, I might enter the room holding my new (or old) label sign but rapidly be able to place it on a bonfire built in celebration of our mutual gifts.

Writing this all down has given me a little more insight into my personal dilemma about accepting those labels and why I feel so enticed into doing so when I've spent a whole career fighting them. What I do know is that we all have to move past this categorization and classification thing somehow. New experts are bound to turn up to tell us how. But for now, I'm tired of "passing". I'm looking for a place to hold the coming out party to celebrate my differences. Maybe if FDR had had friends like the folks over at *Our Place*, he would have gotten into his chair and rolled right on over, in clear view of any and all to see.

**Ruthie-Marie Beckwith, Ph.D.** is a disability rights advocate who resides in Tennessee. She currently helps individuals and families create microboards, a single person provider based on the principles of self-determination.

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## Endnotes

<sup>1</sup> From Beckwith, R. (2003). *The Arlington poems: The struggle for the lives in a state-run institution*. Columbus: OH, Pudding House Publications.

<sup>2</sup> National self-advocacy organization

<sup>3</sup> People First language insists that the person be identified first and then, only if necessary, their disability.

<sup>4</sup> Post traumatic stress disorder

<sup>5</sup> Dissociative disorder, not otherwise specified

<sup>6</sup> Self-injurious behavior

<sup>7</sup> *Building recovery of individual dreams & goals through education & support, a consumer run education program on mental health recovery*, sponsored by the Tennessee Mental Health Association, the Tennessee Alliance for the Mentally Ill, and the Tennessee Department of Mental Health and Mental Retardation.

<sup>8</sup> Consumer/survivor/ex-patient/recovery

<sup>9</sup> Blatt, B. (1981). *In and out of mental retardation: Essays on educability, disability, and human policy*. Austin, TX: PRO-ED.