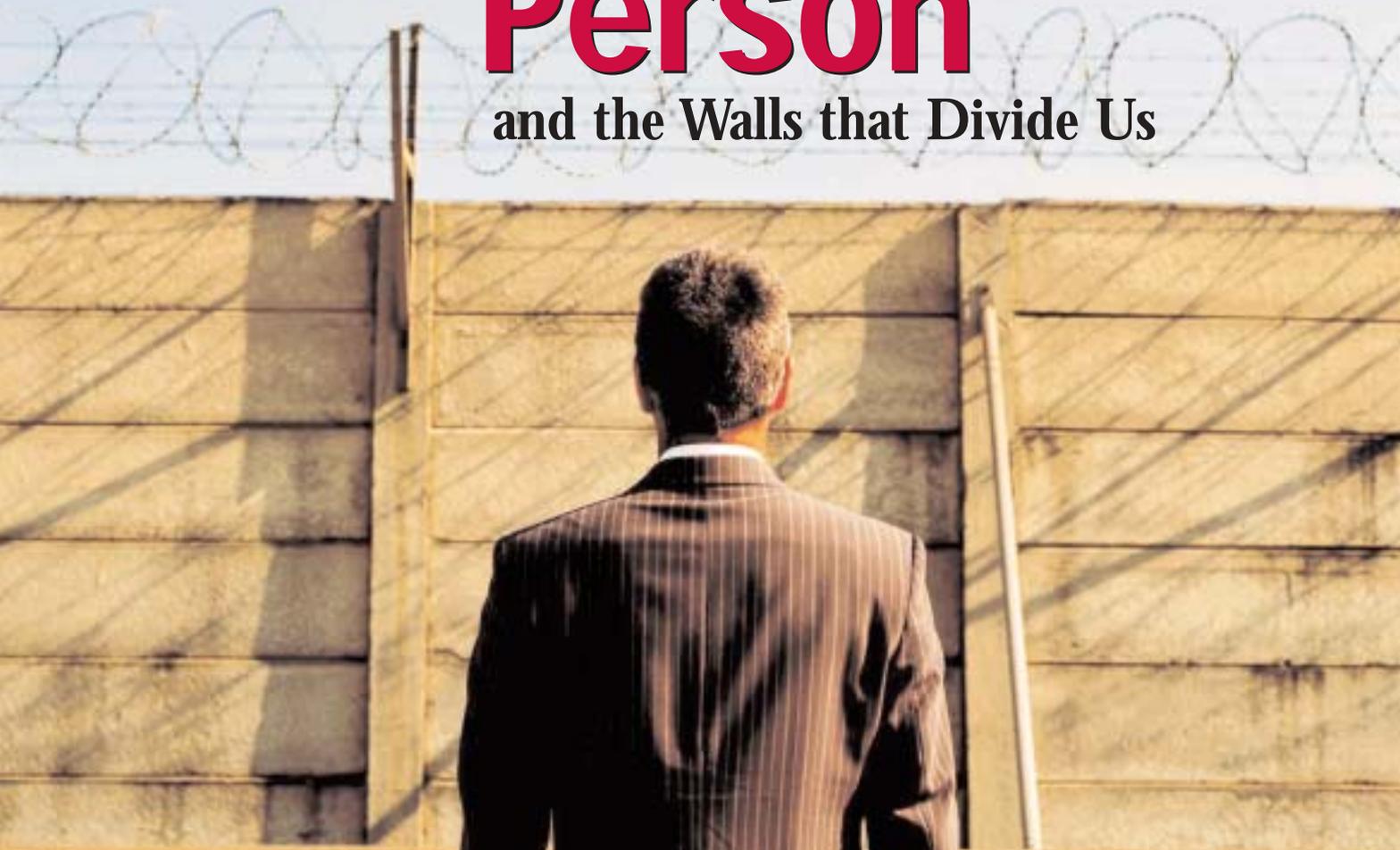


The Decade of the Person and the Walls that Divide Us



About one decade ago, I suggested in an editorial in the *Psychiatric Rehabilitation Journal* that the 1990s should be called “the decade of recovery,” rather than its heretofore declaration as “the decade of the brain.” I made this suggestion based on the increasing attention paid to the recovery-focused writings of people with psychiatric disabilities, and the long-term outcome studies conducted and synthesized by Courtenay Harding and her colleagues.

At the beginning of this century I was asked, based I guess on the fact that I did it before, to give a name to this new decade, the first decade of the 21st century. I suggested, once again in an editorial in the *Psychiatric*

Rehabilitation Journal, that it be called “the decade of the person.” I chose this term because I believed that late in the 20th century we as a field had “forgotten” that this is a person we are trying to help. Somewhat like traditional medicine, the mental health field seemed to be treating people diagnosed with severe mental illnesses as if they were impaired body parts — in this case dysfunctional brains. To me, this partitioning of the person into body parts was part of a legacy in our field of separating people into categories, or said another way, putting up walls that divide us from one another, and from our whole person.

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(EDITOR'S NOTE: This is an excerpted version of the keynote address Anthony delivered at the 2002 conference of the Center for Psychiatric Rehabilitation. One of its main points serves as a thought-provoking follow-up to our coverage of evidence-based practices in the February 2003 issue.)

A person outside of the mental health arena has written eloquently about the danger of erecting walls that divide us. Robert Frost authored a very famous poem about walls that divide us that is as relevant to issues we confront in our field of mental health today as it is to his description of the walls that frame the fields and farms of rural Vermont. Two lines in Frost's marvelous poem entitled "Mending Wall" never leave my mind: "Something there is that doesn't love a wall", and, "Before I built a wall I'd ask to know what I was walling in or out." I wish to speak today about the necessity of tearing down the walls in our field of mental health that continue to wall us in or out, from ourselves and from one another.

Over 30 years ago I became involved in the brand-new field of psychiatric rehabilitation and in retrospect I realize that my first task was to help tear down a wall — a wall that divided how we treated people with physical disabilities who needed rehabilitation and how we treated, at that time, "the mentally ill" who needed rehabilitation. In 1968 I was a Captain in the U.S. Army, stationed at Walter Reed Army Medical Center, working as a psychologist in the Department of Psychiatry and Neurology. We treated soldiers returning from Vietnam who had neurological injuries (e.g., spinal cord injuries, traumatic brain injuries) as well as soldiers who had developed "a mental illness." For those soldiers who had a physical disability, we developed a rehabilitation team of professionals who met with the soldier to help plan his return to civilian life. I recall at the time that their medical treatment was characterized by a great deal of respect and empathy, at least in relative contrast to "the mentally ill." The latter group was treated with medication, received occupational therapy, and did not experience the same interpersonal atmosphere as people with physical disabilities.

When I left the Army and returned to civilian life as a teacher and researcher, my thought was — Does the disparity in how we treat and rehabilitate people with two different disabilities have to be that way? This wall is now starting to come down, and wielding the wrecking ball are members of both groups of disabilities. People with physical disabilities and people with psychiatric disabilities are forming coalitions and advocacy groups to demand that people, no matter what the disability name, are being treated with basic human decency and provided opportunities for rehabilitation.

For most of the last 100 years the walls that separated people with psychiatric disabilities from other people, including other people with disabilities, were very concrete — or perhaps I should say were as obvious as the

fences and locked doors of state mental institutions. But today I don't wish to speak and be critical of the negative impact of the very tangible, solid walls of the institution. I want to speak about the attitudinal walls that divide us, both in the community in which we all live and in our treatment settings; these walls, if left standing, can be as daunting to recovery as are the walls of the institution.

The first wall I wish to speak about is the wall that prompted me to label this first decade of this century the decade of the person. It is the wall of importance we have erected around our biological brains. People with severe mental illnesses are considered, alliteratively, to have a "broken brain." In so labeling we have elevated the brain to prominence, as if by solving the mysteries of brain-behavior relationships, recovery breakthroughs would commence. Would that it were so simple. It is the person, and not the person's brain, that must be our focus in the decade of the person.

I have seen MRI pictures of my own brain. And let me be honest with you — I did not recognize myself! I couldn't find my life, my family, my work! We must tear down the wall that divides our brain from our mind, and that walls us away from the fact that our life experiences and what we make of them can change our very being, as well as our brain.

When I look over our field today I see a wall that is still standing, that one would think would have fallen a long time ago. It's the wall that separates the professional practitioner from the person with a psychiatric disability. This wall continues to be a very strong wall, buttressed in many spots by traditional mental health thinking. Unfortunately, two of the ways we keep mending this useless wall are as follows:

- 1) Our belief that healthcare technology is more important than the healthcare relationship, and
- 2) Our thinking that people with psychiatric disabilities cannot make useful choices, and we need to make them for them.

In the first instance, we act as if the practitioner's knowledge and technology are more important than the interpersonal relationship between the practitioner and person getting help. We know this is not the case from listening to what people tell us. When asked, a majority of people who are recovering from severe mental illnesses will mention that a critically important contributor to their recovery are other people — people who listened to them, believed in them, and supported them in numerous ways.

I have always maintained that the primary source of our learning is not our books and their theories, but the people we are trying to serve and their families. When

given the opportunity, either through their words or their actions, they are trying to help us be better practitioners. A lesson *only* people with disabilities can teach is that people with disabilities are first and foremost people, and not cases or diagnoses. I learned about people with disabilities from a number of good friends who happened to have disabilities, but especially from my close friend Bob. Bob was born without any arms and legs, except for one leg-like, two-foot-long appendage that had three toes. Bob visited me at college and stayed overnight, came to my wedding, graduated cum laude from college, and was a staff member with me at a summer camp for kids with and without disabilities. Bob taught me about people with disabilities, more so than any textbook ever did. He taught me by his actions that most important lesson — that people with disabilities are people first, who only want the same things everyone wants, to live a full life, to love, to laugh, to learn, etc.

A second action of professionals that divides professionals from the people they are supposed to serve is the professional notion that people with psychiatric disabilities cannot make useful choices. I have been writing for over two decades about the importance of professionals doing rehabilitation *with* and not *to* clients, and helping people to develop their own goals. We now have lip service about this concept of self-determination, but the wall is still there.

We take choice away from people with psychiatric disabilities supposedly “for their own good,” when in fact we usually do it for the good of the professional and society. For example, if we can force someone into some program or setting, then we do not have to worry about making that setting more appealing or useful. Also we “blame the victim” rather than ourselves when they don’t attend the program or use the service we ourselves would never use. Also, if people with disabilities are allowed to choose, they may request something that demands that we change our actions or programs.

To me this wall, called “you think you get a choice but you really don’t” wall, is most apparent in how we treat people who are homeless. One of the times we ran into this wall was when we were designing a research demonstration program called “Choices,” a program for people with psychiatric disabilities in New York City who were homeless and street dwelling. We were trying to adapt the psychiatric rehabilitation mission statement (the part that says “help people become successful and satisfied in their *living* environment of choice”) to fit the research requirements of the funding agency, and we came upon a major obstacle. The research agency funding the demon-

stration program said the mission was to help people obtain the “*housing* of their choice.” In contrast, an acceptable outcome based on the psychiatric rehabilitation principle of maximizing choice would be any living environment a person chose (including being not housed and continuing to live on the streets). In our particular research demonstration we chose to be consistent with psychiatric rehabilitation principles, even if this was at odds with the research intent. Our reasoning was that if the street living environment is what some people might originally choose, we would honor that choice and continue to work with them toward other goals, and hopefully at some point a housing goal as well.

No doubt one of the biggest failures of this decade is how we continue to wall out people who are homeless and disabled. For example, when people with disabilities want to work, for the most part we try to help them obtain work. When people with disabilities want treatment, for the most part we try to help them obtain treatment. In contrast, when people who are disabled and homeless want a place to live, what do we do for them? We get them a case manager!

Now when I survey our field I see a new wall going up. It is a conceptual wall called the evidence-based practice wall, whose construction is built on the sensible notion that service delivery must be based on research. The builders of the evidence-based practice wall have already identified certain practices (e.g., ACT, supported employment) that meet the evidence-based practice requirement, i.e., several randomized clinical trials (RCTs) demonstrating a program model’s efficacy.

While EBP is a useful concept, its implementation in this field is premature. This useful idea is becoming a wall that is going up way too fast, faster than the available data would suggest. Some people are using EBP to wall practices out, rather than figure out what can be learned from existing practices that have some data but have not made it over the RCT wall. In contrast, this field was built by people tearing down walls — by working beyond the existing walls — like the originators of ACT did, and building on what we know and *not just how we know it*. Stein & Test had a different vision for their time (i.e., people with severe mental illness could receive mental health-care in the community). Their program was *not* developed based on RCTs, but on a unique vision.

For an EBP to exist in the decade of the person it must show through RCTs how people are helped to recover by this EBP. The EBPs so far identified show how they can reduce symptoms and relapse, and help people work in dead end jobs, *but do not show how they help people to*

recover. Missing for the most part are outcomes like empowerment, self-esteem and meaningful work.

Interestingly, much of the knowledge base guiding our field was not researched by EBPs. For example, the lack of a strong correlation between skill and symptoms, the fact that people can and are recovering, the lack of generalization from institutional living to community living, the importance of the helping relationship, etc., are not the result of EBP research. What then to do with the EBP wall? We must tip it over. We must lay the wall down on its side and make it one of many knowledge highways to client outcome. And emphasize that it is but one of many pathways to knowledge; there are useful ways of knowing about what works other than the RCT highway (surveys, observational studies, correlational research, etc.). Indeed, it is these ways of knowing that has allowed the RCT highway to be built at all.

Even laying the EBP wall on its side and considering it only one of the highways to knowledge still concerns me. My concern is that we are building the EBP highway out of the wrong substance. The substantive component should not be evidence-based *practices* but evidence-based *processes*. Currently in EBP research we are focusing on practices or what I would call program structures, e.g., caseload size, team composition, number of team meetings, etc.

I would argue that in the mental health field our investigations should focus on the *process*, and not the program structure. Mental health interventions that appear different based on their program structure, may actually be very similar in terms of the *process* that is occurring between the practitioner and the person being served. While the program structures have been examined for their conceptual and empirical differences, a more appropriate focus of study, independent of the name of the program, may be measures of process, such as the nature of the interactive relationship between the practitioner and service recipient, the practitioner's use of advice and coaching, collaborative goal setting with people, skill teaching, developing a person-centered plan, providing environmental accommodations, the service recipients' opinion about the practitioner, etc.

The study of evidence-based *process* does not relegate program structures to insignificance. I would suspect that certain program ingredients (low caseload size, people with disabilities on staff) allow critical processes to occur

more effectively. Program ingredients are then viewed as supporting particular processes around which the evidence is built. To continue to study program structure alone in order to differentiate models and their unique impacts on people's outcomes is not where the real action may be. It is time to emphasize the human interactive process, as it occurs within differing programs, as a fundamental target of scientific research.

For over 30 years I have heard and read many false pronouncements about the people we serve that have only divided us. These statements have kept us, helper and service recipient alike, from being the people we can be. Pronouncements masquerading as fact have allowed us to hide behind the wall of inaction and the status quo. I wish to close with some of the most outrageous pronouncements I have had spoken to me over the last 30 years. I have categorized these pronouncements somewhat chronologically to reflect how far we have come as a field and how far we need to go:

Early pronouncements — less often heard today

People with severe mental illnesses are sick, not people with disabilities.

People can't live in the community.

People can't learn skills if they are symptomatic.

People cannot be successful in real work or school environments.

Later pronouncements — still used by some

People can't make realistic choices.

People need ongoing, continuous, long-term care.

People can't recover.

Current pronouncements — still very much in vogue

People can't leave homelessness without first receiving extensive mental health services.

People need evidence-based practices in order to help them recover.

People can't hold jobs that we think are too demanding.

I hope when you hear these mythical pronouncements (whether they are old ones or ones you have not heard before) you will destroy and bury them. Let us destroy some walls the next several days and for the rest of our lives — walls that keep both helpers and the people served from being the persons they need and want to be. ☺

A complete Webcast of "The Decade of the Person and the Walls that Divide Us" is available at www.bu.edu/cpr