Rethinking Rehabilitation: Freedom

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Good morning. It is a pleasure and an honor to have this opportunity to speak with such a large and diverse group of people representing 68 countries from around the world. The task that Rehabilitation International has set before us at this 20th World Congress is to Re-Think Rehabilitation. I have been asked to speak on the topic of Re-Thinking Rehabilitation from a user perspective, with an emphasis on obstacles and realities. I would like to begin by dedicating this talk to people with disabilities who are in institutions, nursing homes, custodial care facilities and other places set aside for unwanted and devalued people. Of this I am certain: no progress will be made in rehabilitation until we close down these institutions of human misery and handicaptivity (Gwin, 2001).

The title of my talk today is Freedom. Freedom is elemental. Freedom and humanity are inextricably linked. When freedom is diminished, humanity is diminished. When freedom is exercised, human life flourishes.

Freedom is like good soil. Our humanity seeks to root itself and grow in the good soil of freedom. Oppression is like a drought, parching the soil so that freedom is denied and humanity withers. If we plant a seed in parched soil and it fails to grow, do we ask what is wrong with the seed? No. We realize that life can not take root in a parched soil. We don't blame the seed. We look, instead, at the environment in which the seed is being asked to grow. We conclude that the problem is drought. And so we set about watering the soil, restoring freedom and working to end oppression. And then, like a small miracle, human life takes

root and grows again. Deeply rooted in the good soil of freedom, human beings can pursue the ontological vocation of being and becoming more fully, more complexly, and more joyously human (Freire, 1989).

Re-thinking rehabilitation means thinking about how rehabilitation services contribute to the drought that strips away freedom and makes it so very difficult for those of us with disabilities to flourish in this world. If rehabilitation is to become part of the solution, it must become emancipatory and must work to end oppression. In human terms, oppression forbids the oppressed to be and to become (Freire, 1994). Those of us with disabilities are too often forbidden our freedom to be and our freedom to become. Let me give you an example from my own experience. Let me tell you about a time when I was stripped of my freedom to be and to become.

When I was seventeen years old and still in my final year of high school, I experienced psychosis and was brought to a mental institution. Once there, I was diagnosed with schizophrenia. Once diagnosed, the label of schizophrenia took on a master status in terms of my identity. The fact that I was a good athlete, that I enjoyed being in nature, that I was the oldest child from a large working class family was of little interest to the professionals around me. What mattered most in their eyes was that I was a schizophrenic.

Professionals' reification of the diagnosis of schizophrenia was oppressive because it subjugated my humanity such that everything I did was interpreted as part of psychiatric disability. It was as if professionals, and later friends, family, teachers and others, put on a pair of warped glasses and began to view all of my behavior through the lens of disability. Once my diagnosis was known, all of my behavior was open for pathological interpretation. For instance, I have always been a quiet, contemplative type of person. Even as a kid I had this lovely quality of being drawn to contemplate nature and the world around me. However, once diagnosed with schizophrenia, these same qualities were interpreted through the

lens of disability. Once diagnosed with schizophrenia, I was not a quiet and contemplative kid anymore. Instead, rehabilitation staff would write in their notes that I was guarded, suspicious and aloof.

Here is another example. I was an active, robust and athletic kid who was always on the move. I remember that on rainy days, when I was stuck in the house and irritating the family with all my running about, my little Irish grandmother would say to me, “Ah Patricia you’ve got the jig. Go outside and blow the stink off of you!” This meant “you are being a nuisance. Go out in the rain and run around until you tire yourself out. Then come back inside when you can behave.” Now I can guarantee you that once in a mental institution, diagnosed with schizophrenia, the rehabilitation staff were not writing notes saying, “The patient has the jig. We recommend she go outside to blow the stink off her!” Instead, the very same behavior and personal characteristics were now being viewed through the lens of disability. Through this lens, rehabilitation professionals saw not a person who had the “jig”, but a schizophrenic who was agitated and aimlessly ambulating along the crowded corridors. The cure was not to go out and “blow the stink off of me”. The cure was restraints.

What I am describing here is oppression manifest as a threat to my freedom to be. I am describing oppression as a threat to my freedom to be the unique individual that I am. I am describing oppression as a threat to the freedom to be incurably me – you know - me, the “jiggy” kid who was also a monk-like contemplator of my world. I am describing a type of violence. The violence of being dehumanized and having my individuality reduced to a generic diagnosis. I am describing the arrogant and unapologetically clinical gaze that captures me, re-interprets me and hands me back to myself as damaged goods; disabled; off-spec; not-right; broken-brained; neuro-chemically imbalanced; genetically defective; a special person with special needs, requiring special services in segregated places.

I am describing an insidious aspect of oppression in which my freedom to define myself and my world was threatened. In it's place I was handed an image of myself as crippled and disabled. Professionals assumed that I would take their distorted image of the generic schizophrenic and make it my own.

It was assumed I would be colonized by this image or professional interpretation of me. And in cruel twist, if I resisted and said "No, this distorted image is not me", then that would have been interpreted as further evidence of my disability. In other words, if I had said "No, I am not the distorted and disabled image of a schizophrenic that you have handed me," if I refused to be colonized in this way, then the professionals would have said I lacked insight into the fact that I was ill. They would have said I was in denial of my disability. They would have continued to ply me with more services until someday, perhaps, I would abdicate my freedom to be who I was, and accept their diagnosis as my identity. This, in their eyes, would be celebrated as progress, as insight, as overcoming denial and as acceptance of disability. However, from the user perspective such an event is not celebrated. From our perspective such a capitulation of individuality is death-making, spirit-breaking, a time for weeping.

And it is not just people with psychiatric disabilities who have experienced the loss of the freedom to simply be. The phrase "oppression forbids the oppressed to be" takes on a frighteningly concrete meaning when applied to those who were born different than typically developing people. My friend with spina bifida recounts how her mother was advised to abort her and, once born, her parents were advised to have her institutionalized. The assault on her freedom to simply be, began while she was still in the womb. Members of the deaf community have known this assault and theirs has been a powerful struggle to re-claim their freedom to be incurably themselves. Oppression does not distinguish between artificial groupings of disabled people. And so people with physical, cognitive, psychiatric, and sensory disabilities all know something of what it means to live a life of forbidden being.

It is not just the freedom to be that is oppressed. Oppression forbids our becoming as well. My earliest experience of forbidden becoming occurred after I had survived a number of institutionalizations and ongoing rehabilitation services in the outpatient department. I remember going to one of my rehab appointments and asking a psychiatrist what schizophrenia was. He told me I had chronic undifferentiated schizophrenia and no one gets well from that. He told me that I would have to continue taking medications for the rest of my life. He had low expectations for me. He told me I needed placement in a half way house so that I could learn to cook, clean, do chores and master my ADL's, or activities of daily living. He said I must go to a day program designed especially for people like me. In the day program, I could learn to socialize with people just like me and perhaps even join a prevocational group with people just like me. He told me to avoid stress and to settle for a life of coping. He said that was the best people like me could hope for.

I have come to call his pronouncement a prognosis of doom. In one colossal fortune-teller moment, I lost my future. I lost my freedom to become. I would not be the athlete I aspired to be. I would not be the coach I dreamed of being. My future was not mine to make. My future and my fate had already been prescribed in a textbook. My future was not ambiguous and uncertain like the future of non-diagnosed people. My future was not an unfolding adventure. My future was not a question in search of an answer. My future was not full of promise. My future was not an open possibility into which I could project my dreams and human aspirations.

No. Losing my freedom to become meant my future was sealed. My future had already been mapped out by professional opinion that said people like me should not be free to live among other citizens. And the rehabilitation system, into whose care I was committed, was structured – however unintentionally – to keep people like me trapped in poverty and futureless futures. That is, being forbidden to

become is systemically enforced by certain rehabilitation policies, programs and financing mechanisms.

There are over 43 million people with disabilities in my country. The vast majority of us live our lives in enforced poverty, subsisting on disability checks of about $580 dollars a month or about $7,000 dollars a year. It's nearly impossible to make your own future when you have no disposable income and must choose between buying food to eat or soap to bath with.

1.9 million Americans with disabilities live in nursing homes at an annual cost of $40,784 dollars per person, per year. It only costs $9,692 dollars a year to support personal care attendant services to people in their own home. Despite the evidence that quality of life is superior with less expensive, proper community supports, money continues to flow into nursing homes. That is systemic oppression. It's impossible to make your own future when you are condemned to live in a nursing home and can't even choose who you will live with.

Similarly, over 150,000 Americans are confined in mental institutions at an average cost of $58,569 dollars per person, per year. The average cost of supporting people with psychiatric disabilities in the community in the state of Florida is $1,693 dollars per year. It's impossible to make your own future when you live in a mental institution and the only people that associate with you are people who are paid to work with you.

There are 77,618 Americans in state institutions for people with developmental disabilities at a cost of $82,228 dollars per person, per year. It only costs $27,649 dollars per person, per year to provide the most intensive and expensive 24-hour support to persons with developmental disabilities in their own homes. It's impossible to make your own future when you live in an institution and you don't have the keys to the door and aren't even free to go outside for a walk.

Over 70% of people with disabilities are unemployed and many more of us are underemployed. It's nearly impossible to make your own future when you are not part of the economic fabric of the culture you live in.

In the state where I live, people with psychiatric disabilities die on average 8.8 years younger than non-diagnosed people in the general population, with a significantly higher frequency of our deaths due to poisoning by psychotropic drugs or drug combinations. (Dembling, Chen & Vachon, 1999). One in four people with psychiatric disabilities who are prescribed antipsychotic medications will develop a neurologically based movement disorder called tardive dyskinesia. It's hard to make your own future when iatrogenic brain damage is hailed as a breakthrough in the treatment of mental illness and when you cannot access decent medical care to safeguard your own health.

Life lived within the confines of the human services and rehabilitation landscape is a life in which the freedom to become and to make your own future is diminished. Somehow I had intuited that. When the psychiatrist pronounced his prognosis of doom – when he said I was a schizophrenic and that's all I would ever be - something began to stir down deep inside of me. A scream, a cry, began to form within me. "No, you are wrong. You are wrong. I am not a schizophrenic. I am more than that. I am a person, not a disability." That silent scream was both a rejection of his prophecy of doom and a simultaneous affirmation of my worth and dignity. That scream, that cry announced that I was free. I was not dead yet. I was alive and well and resilient and intent on fighting for a life that had meaning and hope.

I want to suggest that we begin to rethink rehabilitation from the perspective of that scream. That cry forms the common ground of our humanity. I know you understand it even if you have never been diagnosed with a disability. There is something universal about the cry that resists dehumanization by asserting I am a person, not a thing.

A few years ago I conducted a survey of people with psychiatric disabilities who were living in community based residential programs. Feel the scream catch in your throat as you hear these spirit breaking statements made by rehabilitation counselors:

- It would be unethical for me to allow you to go to college. You have to learn to set more realistic goals for yourself.
- People with your disability can never get a driver's license. Why put yourself through that kind of stress. Learn to use public transportation.
- Don't reach for the stars. You'll only have further to fall.
- For a schizophrenic you are doing very well!
- You are not that high functioning. You should try a volunteer job.
- I understand that your medications take away your sex drive. You'll just have to learn to get used to that.
- My taxes pay for your disability benefits. You're just wasting my money.

Or consider this true story. A woman in her mid twenties with a psychiatric disability met with a team of rehabilitation specialists and shared her good news with them. "I am having a baby," she said with a big smile on her face. The physician at the meeting turned to her and said, "You are not having a baby. Those are just a collection of small cells in your uterus that must be removed, and your parents are having arrangements made for that procedure."

Consider this story that a friend told me. When he was fifteen years old he broke his neck and was paralyzed. While undergoing rehabilitation a group of students came into his room, led by a senior rehabilitation instructor. The instructor began talking with the students about the quadriplegic with the C-3 fracture who lay on the gurney before them. Without asking permission, the instructor ripped the sheet off the fifteen-year-old boy and exposed his naked body for all to see. The teenage boy began to scream and scream and scream.

In response to the boy's scream, the instructor arranged to have a tranquilizing drug administered to silence the boy, while the students watched attentively and learned.

I am proposing that we begin to rethink rehabilitation from the perspective of a million screams and from a million muffled screams – screams pressed into pillows, choked back down the throat, swallowed for fear of exploding into rage - the muffled cry of the young pregnant woman who was told to abort; of the one who wanted to work and was told to volunteer; of the one who wanted to get her drivers license but was told she couldn't handle the stress; of the one who wanted to leave the nursing home but was told she wasn't ready; of the one who wanted to try and was told that it was too risky; of the one who said I am a Pat and was told she was a schizophrenic; of the one who said I want a home and was given a nursing home instead.

There are nearly one thousand of us in this room today representing 68 countries. Chances are your native language is not the same as the person five rows behind you. Yet I would argue that the language of the scream is a universal language. It is the protest, the rage, the agony, the voice, the cry for dignity that rises up when our elemental freedom to be and to become is assaulted.

When you feel the cry awaken within you, trust it and know that it is signaling the eruption of the inhuman and the inhumane into the rehabilitation setting. That cry signals the violence of dehumanization. Rethinking rehabilitation means we must examine the ways in which disabled people are transformed into dehumanized objects to be acted upon as opposed to fully human subjects who can act, and through action change their situation (Freire, 1989). We don't get rehabilitated in the sense that cars get tuned up or get repaired (Deegan, 1988). People with disabilities are people. When we forget that people with disabilities share a common humanity with all people, then the human is stripped from the human

services and the stage is set for the emergence of the inhuman and the inhumane. The inhuman and the inhumane emerge from that rupture which occurs when one human being fails to recognize and reverence the humanity and the fundamental sanctity, sovereignty and dignity of another person (Deegan, 1996, 1993, 1990). We must rehumanize the practice of rehabilitation.

Disabled people are not things needing to be fixed. No one in this room would doubt the veracity of that statement, yet the bio-mechanical metaphor continues to be the root metaphor of rehabilitation. Sometimes reading a rehabilitation textbook is like reading the technical plans for an automated assembly line in a factory. We talk about hiring rehabilitation *workers* to fill *shifts* to provide *24/7 service* to service *users* who are placed in available *slots* that fill *quotas* and meet *performance standards* so that *billable hours* can be *accumulated* so that reimbursements can be invoiced, and the money flows, and the wheels keep turning, until rehabilitation emerges as a giant machine that seems to exist in order to perpetuate it's own existence.

It's time to get rid of the biomechanical metaphor in rehabilitation and to replace it with a more humanizing approach. It's time to recognize that it is not disabled people that are broken, it is the rehabilitation machine that is broken. Re-thinking rehabilitation means thinking outside the machine. Thinking outside the rehabilitation machine means no more broken people in need of fixing. It means that we stop treating disabled people as special people who have special needs, that require special services in segregated programs (Gwin, 2001). The moment we begin talking about disabled people as special people with special needs requiring special services in segregated programs, we have already begun the process of dehumanization upon which the biomechanical rehabilitation machine runs. To say disabled people have special needs is to set us apart as the Other and that is the slippery slope upon which we descend into the oppression of disabled people (Deegan, 1992).

Our needs are not special. Our needs are the same as your needs. Our need, indeed our ontological vocation, is to become more fully, more joyously, more complexly human.

And that is why those of us with disabilities look at rehabilitation services that are oppressive and say, we don't want what you are giving, we want what you have got. You have got your freedom. You are free to pursue a life of your making. If you are giving us a nursing home placement to fulfill our special needs we say, we don't want what you are giving, we want what you have got. We don't want a placement in a nursing home. We want what you've got: a home. A place that is our own. A place where we own the keys. A home where we are free to make our life, to associate with those whom we love, and where we can open and shut the door all by ourselves.

We don't want to be the widgets inserted into rehabilitation program slots. That is the dehumanizing path that ultimately is oppressive because it robs us of the freedom to be for ourselves and to become. It's time to stop funding rehabilitation *programs* and to start putting rehabilitation dollars directly into individualized budgets that people with disabilities can spend as part of self-directed care plans. Self Directed Care is the future of rehabilitation. In self directed care we take the money out of the rehabilitation machine that serves to perpetuate itself, so that those public dollars can come directly under the stewardship of people with disabilities and when applicable, their families. Self-directed care eliminates the programmatic middleman. Let these rehabilitation dollars flow through a fiscal intermediary and into individualized budgets to become the currency through which people with disabilities can freely purchase the supports we need in order to be and to become. Let these dollars elevate us from the oppressed status of service users and patients, to the empowered status of consumers whose spending power will drive the evolution of rehabilitation services.

What do people do when they are directing their own care? The Florida Self-Directed Care initiative for persons diagnosed with psychiatric disabilities has enrolled just over 100 participants in the past two years. Participants in the self-directed care initiative develop their own recovery plan and specify the resources and supports that they will require in order to live their lives in the community. A flexible, individualized budget is then arranged through a fiscal intermediary. Budgets are flexible because goals and priorities change over time. People are free to purchase resources, services and supports as long as those purchases are specified in the individualized plan. People are free to pool their money to create services, supports and resources if they don't already exist.

Early data from the Florida Self-Directed Care initiative indicate some trends in the choices that program participants are making. People are unbundling services. That is, they are not purchasing one-stop shopping arrangements that are so prevalent in rehabilitation service programs. Instead people are choosing to purchase supports and services in more integrated settings. For instance, instead of going to day treatment, people are going to a local community college for an adult education class in pottery, yoga, piano, cooking, creative writing or computer skills. People are getting their cars repaired so they can visit and socialize with friends and family. They are purchasing passes to the movies so they can go on a date and get a romantic relationship started. People are buying computers and internet access in order to communicate and learn with others. People are seeking out psychotherapy and are exercising choice around what psychiatrists they prefer to work with. And people are buying some nice clothes so that they can take pride in how they look and are seen by others in the community.

Other self-directed care programs have been shown to work for people with physical disabilities, cognitive disabilities and developmental disabilities. The Center for Self Determination (http://www.self-determination.com) under the leadership of Thomas Nerney (2004a, 2004b, 2003, 2001, 1998) has proposed

solutions to many of the policy and funding challenges to implementing self-directed care for people with developmental disabilities.

We know how to do it. We know the promise self-directed care holds. Re-thinking rehabilitation means getting on with the work of reforming the infrastructure of rehabilitation policy and funding so that self-directed care opportunities are available to all people with disabilities. Self directed care is the not the end point. It is the means through which we can be self-determining. It is the way that those of us who are labeled with disabilities can exercise our freedom to be incurably ourselves (Gwin, 2001).
Thanks.

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