



EMPOWERMENT: THE NEXT CHALLENGE

This is such a nice sized audience. What a great turnout for the Ontario Brain Injury Association. I really salute Ray Rempel, President Bev Mantell and the staff here at the Ontario Brain Injury Association, for getting together, not only an exciting conference, but one that I understand is standing room only. I certainly also salute you, the participants. I know how valuable your time is and how difficult it is to get time away from your busy schedules to come here today to talk, to learn, to dialogue, to share and compare. Essentially, that's what I'm here for as well. I don't come before you as any kind of an expert, as much as I come before you as a person who has a passion about injustice. A passion about what's happened to people who have disabilities in this country, not just with head injuries but with disabilities in general.

I see that a lot of the issues that are occurring in the head injury movement today are related to the kinds of things that have happened in the past to other disability groups. They are the reasons why we see people with disabilities as second class citizens throughout Canada, the United States, and in fact the world. In this spirit I'm going to share with you some ideas and thoughts I have about this issue of devaluation. I'll share conclusions I've come to as I've looked around for the last seventeen years or so that I've been involved in the disability movement. I'll attempt to articulate some of the reasons why I think we're at the place we're at. Along with the negative aspects of this kind of analysis, I'm going to also share with you why I think we can move forward and why I think tomorrow is so much brighter for people with disabilities throughout North America. Consequently, I'm going to share with you some ideas, concepts and thoughts that I've generated, some that are certainly viable concepts from other struggles and other minority movements that cause a "gestalt" in my thinking as to where we need to go. So, without further ado, let's talk about the issues.

Einstein! What a great thinker he was. Einstein, a great humanist, a passionate, caring person. In 1948, he said that "man was here for the sake of other men", and certainly I believe this holds true. In head injury we wouldn't see the number of survivors today if it wasn't for caring, compassionate individuals who work with people, upon injury, and help to restore their lives. Consequently, we are here for the sake of other men. But there's a time and a place, I think, in rehabilitation, where we helpers need to back off, where we must recognize that people should take charge of their own lives. In fact, our role as helpers is not just to fix people, but to launch them as well. I think if we have had any problems in the disability movement in the past it's been because we've held on too long. We have in fact created too much of a grip on people with disabilities, to the point where they've not been able to rise above the second class citizen role that they get cast into upon the advent of their injury.

In my talk I'm going to build a case for this but I think Einstein points out how we can get distorted in terms of thinking about our mission. What is the real role of our helping profession? I really perceive that rehabilitation and all things about rehabilitation are related to four basic themes. In fact, I believe these four things are essential to every person in this room.

- Where people live
- What they do
- Who they relate to
- How they relax

Let's review these four themes.

Every one of us struggles for the concept of having a place to live that we control, a place in which we can have charge of our lives, can kick back and don't have to be on display. A place that can in fact be private. Many of us, when we finally get back to our private environment, wherever that may be, become a different type of person. Many of us would probably not want to share some of our rituals of privacy with most other people. Privacy is very important for us, to have the opportunity to kick back and get into clothes we feel good about, to set the environment that we want our environment to be. So where one lives and how one lives is a critical and very important part of the rehabilitation process. It's what we're about.

The second issue, "what we do," is equally important. Every person in this room is interested in or concerned about things to do during the day that are important to them. Equally important is the way society perceives these activities. None of us want to do anything that society perceives as devalued. All of us strive for work or a job or an activity that is going to be what we call valorized.

I'll discuss valorization in just a minute. Meaningful daily activities are an essential thing we strive for. It is another important part of the rehabilitation process—getting people prepared to go back to work environments and meaningful day activities.

Thirdly, comes relationships. Intimacy is a viable part of the rehabilitation process. In fact, intimacy is essential to every person's survival. Without intimate relationships none of us could really survive. One just needs to look at the literature that deals with young children being taken from environments that are intimate and put into environments that are not very intimate. People who have no opportunity for intimacy, holding, caring, loving, telling secrets to, being close to, do not survive very well. In fact, some studies show that people die when they don't have that particular piece of the rehab puzzle.

The fourth theme deals with rejuvenating activities—the opportunities to get up and get ourselves back in the race. "Miller Time," for those of us who know that commercial, is an example. The chance to relax and not be on display.

Now these four things are absolutely essential for every person in this room and are what rehabilitation is all about — to restore the individual to these four things. But I submit to you ladies and gentlemen, that if you look at the outcomes in head injury rehabilitation throughout North America, here in Canada as well as in the United States, you're going to see and find that we have not done very well in these four areas for people with disabilities. This is especially true for people with head injuries. Let's review some of our outcomes.

Where people live. In terms of long term opportunities we have very few options beyond going back to somebody's home, whether that be with their husband, wife, mom, dad or nursing homes. Now, in some cases, moving back to

the parental home is a tremendously appropriate and right environment. In other cases it may be the worst. I talk to a lot of families around the country who tell me that after the “honeymoon” period when their son\daughter, husband\wife comes back home, when the behaviours and the activity patterns are different, the “honeymoon” starts to wane. Often at this point family pathology sets in. The family starts to break down and serious problems start to occur. Now this doesn’t happen all the time, but when it does happen, there are very few other options that are out there in terms of long term supports for people with disabilities, other than nursing homes, and we all know that these settings are inappropriate.

Secondly, in *meaningful daily activities*, we have had equal failure. Obviously a lot of folks with head injuries come to us out of decent jobs, wherever these may be. After we have saved the person, we try to get them back on track to those jobs. Yet, we are having serious difficulty getting folks back into these jobs. I know you know that. Just look at the literature. Look at George Prigatano’s research. I recently talked to a friend of mine, Dr. Keith Ciccarone at JFK Rehab Centre in New Jersey. He shared some tragic data from a five year longitudinal study where they followed fifty people who were head injured. In their sample they had forty-two of those fifty folks back to jobs immediately after discharge. Five years later, do you know how many were working out of those forty-two that were initially placed? Four people were working. *Four People!* I submit to you and suggest that that’s not very good outcome data.

Intimate relationships has probably been the most tragic area of failure. If you sit down and talk with somebody who’s been ripped apart from their environment, ripped apart from their social activities, and ask them how they feel about themselves, or who their close friends are, or if they have someone to hug and hold and to love and to cherish, you will find the outcomes to be pretty sad as well. We haven’t done a real good job helping people restore relationships. After head injury, most people lose their close friends and have difficulty getting new ones.

And then certainly the fourth category, *rejuvenating activities*, has been equally difficult for many reasons, so the bottom line about this is, we see a million new head injuries a year in the United States, and of those million head injuries close to 200 or 250 thousand require long term supports. Yet we haven’t been very successful in our long term outcomes. This tells me we need to take a serious look at what we’ve been doing. We need to ask ourselves what is wrong with our models and why we’ve been doing it that way. Lastly, we need to identify what we have to change in order to enhance those outcomes. We must step back and inspect what is going on in the rehabilitation system and the traditional medical model. We need to wonder what we fundamentally have to readjust in order to bring these four things to fruition for people we are about. To this end, let’s talk about the system. Let’s open ourselves up to what’s been happening.

In most of our human service planning today, as we plan for and carry out supports for people with disabilities in North America, there are essentially three models of service upon which we develop programs. The first is the exalted medical model. The second one is the economic model and the third is the maintenance model. The medical model is about fixing people. The economic model is about becoming a productive and contributing member of society. Finally, the maintenance model is about taking care of people. Often, however, individuals remain in a maintenance kind of mode. Let’s inspect each of these three. Let’s talk about what these models are, what the good parts of these models are and what the bad points are so that we can start to frame and crystallize a new model. We need a new way of thinking, a new approach so that the outcomes can get better.

First, the medical model. If it emphasizes limitations on physical challenge, then you are limited. If you can’t move your arm the full 180 degrees or whatever, you are limited. This immediately creates a sense of devaluation. If I’m not able to move my right arm 180 degrees, I am less than those who can. This doesn’t mean that physical therapy is bad, rather what I’m trying to capture here is a theme, a sense, a mindset that influences people. Let’s keep that

in perspective. Clearly, the medical model stresses a causal relationship to origins and outcomes of the disability. If an individual had frontal lobe damage then the neuropsychologist will tell you the person will have problems with judgment, seeking bits of information and various types of cognition. In this case it's a causal relationship between frontal lobes and the ability to think. Now this is true in many cases. In a lot of cases there is a causal relationship between perspective, the prediction and the outcome. You know there are families who are going to inform you that what they've been told in the hospital by the neurologists and neuropsychologists and what came to pass wasn't consistent. I know that there are stories like that, I hear them all the time. So we know that we're dealing with something that is relatively imprecise. We don't know a whole lot about the brain. We're still learning about the brain, yet what happens is, given these predictions, we start to think of people in the anticipated outcome. This creates an image, stereotype, and expectation. The family is told something that everyone sort of hangs on to. The treatment comes from a diagnosis. Thus, if it's a head injury, the person should be treated in the head injury ward. If it's a spinal cord injury, put those folks in a spinal cord injury ward. If the person has a developmental disability, then of course they go with those types of people. The treatment is from a diagnosis. This implies that people who have that diagnosis are all very, very similar. In some cases it's true, in some cases it's not true, but again it creates a trend. It emphasizes the concept of the sick role. The medical model says: "I am sick, you are the expert, you know best, make me better." Now there is another important corollary. It follows that, when I'm sick, I surrender autonomy to the expert. In this surrender, I lessen my power; I lessen my value. When the individual surrenders to the expert, the implication is that the patient doesn't really know and just adapts and adjusts. So here we go, the experts tell us that, if a person has a head injury, they're not going to be able to "X Y Z". So mom, dad, husband, wife, don't expect "X Y Z", from this injured person. The individual will have to adapt and adjust to what they can't do.

Now, when you examine the medical model, you will find that the expert frames the problem around the person with the disability. They are the problem. Their brain is the problem. The problem resets in their head, although there may be some other physical kinds of physical associations. Essentially, however, the problem is the person. The problem is the person and this starts to create a mindset.

So, what's the solution? Well, we classify, train and segregate these people. We do this so we can try to fix or treat them. We know they're all alike because their brains are all damaged in the same place. And who's in charge of this, the professional of course. The neuropsychologist, the neurosurgeon, the M.D., the Ph.D., the RN, whoever. They're in charge of this because they've studied brains, they've read books, they've been to classes, so they understand what's happened here. They take charge of that. And of course the family and the individual surrender to those experts. They surrender power to the expert.

So now, what's the outcome? Well, you know, we try to fix this person the best we can and as far as we can. And if we can't fix them any more than money allows, and money is the key critical piece here, then they're just going to have to accept what they can't do, adjust and adapt.

Now once the person leaves this medical model, they get thrust into the economic model. In the economic model the individual is judged upon by looking at their productivity. Is the person productive? How productive can the person become? Can we get them to be more productive? The swing side to this is that, if the individual is not productive, vis a vis, the standards of the system, they are "worthless."

To this point I have to tell you a little story when we start thinking about the economic model. I had a family who came to me with a son who was fourteen years old and had a severe congenital disability. He was severely disabled from the time he was born. The family just could not provide supports for him and he was institutionalized at an intermediate care facility. One day when he was thirteen or fourteen, he aspirated on some food that should have

been pureed and he passed away. The family came to me very, very sad. They thought there had to be some message from their son's death. They wondered if I could help them do something about it. I suggested we talk to an attorney. We went and talked to a friend of mine, an attorney, a very sensitive disabilities attorney. I asked her what she thought about this case, if there was anything we could do to get restitution for this family. The attorney sat back, looked down a little bit and said, "I'll tell you what, we can take this case and bring it to a jury, but I'm going to tell you right now, the jury is not going to award anything. In fact, we probably will not win anything in this case, mainly because the individual is perceived "worthless." In fact, and this is what got me in the gut, my friend said that the jury will probably say that it was good that the individual died because the state was financing a portion of his care. Economically it was good he died because now the system didn't have to worry about paying for a human being's life. The economic model is powerful, very powerful. It puts worth on productivity. If you can run, dance, jump, think, do all those wonderful things, you are valuable. If you can't, you are not as valuable. It is a clear message.

Now, in the economic model, we often get decisions made about what a person can do by Vocational Rehab experts. But you know those people are equally tainted. In many cases the expert is conditioned to think about people in boxes. And so the pre-set judgments are coming from both sides. The vocational rehab counsellors, in many cases, might be perceiving this individual out of their mind set of head injury. Mentally retarded people should become dishwashers, right? Folks with visual impairments should make brooms, and individuals who have hearing impairments should work in loud factories. But folks with head injury... What should we do with them? Where should we put them? That kind of thinking starts to influence decisions.

Now again, I don't mean to insult anyone who spends time in vocational rehabilitation; that's not my agenda. My agenda is just to think about how we box people and how we create some of the mind sets. In the economic model, the problem is the person who can't get a job. Where's the problem? In the person's capability. What's the solution? We try to teach them a new skill based on what we think they can do. And then, who should be in charge of that? Well, the vocational rehab specialist who has read the vocational assessment. And then finally, what's the outcome? Well, we get jobs for those who are capable, and we'll try to put the rest who aren't capable of handling real jobs in the sheltered workshops. And for those who can't even do sheltered work? Well, for them it's off to the maintenance model. And of course we emphasize the maintenance model which is to take care of the individual.

In the maintenance model, the services are rooted in charity. Something very basic and humble. In the maintenance model, we don't want to spend too much money on them since they're really not that productive. Let's just take care of them so that they don't get into trouble. The problem in the medical model is the person needs care. Where's the problem? It's in that person of course! Their arms don't work, their head doesn't work very well, their eyes don't work—that's the problem. And what is the solution? Well certainly we don't want to spend too much money. We don't want to put too much money into human beings, because, God forbid, it's going to cost more money than is cost effective. We know that some planner in Ottawa or Washington, D.C. will tell us that, in fact, we're going over the boundary here. And finally, who's in charge of it?... The benevolent caretaker of course. You know, those folks who are very humble and go to work every day. They're very *special people*, aren't they special? Don't you get that? You hear that from people all the time. Doesn't it go something like this: "What do you do Al Condeluci?" "I work for United Cerebral Palsy. I work with folks with disabilities." "Aren't you wonderful. Aren't you some special human being to give your life to this!"

Come on, you get it, I get it. We get that stuff. Where's the mind set on that? The mind-set is basically benevolence, it's sadness, it's pity and it's charity. That's where it comes from. Yet we're talking about human

beings here, ladies and gentlemen. And finally, what about the outcome? Blind acceptance. Don't challenge this. For God's sake—be happy! Don't question this.

But, let's question this. Each of these models has a micro focus. With the medical model, you fix the person. With the economic model, you fix the person. With the maintenance model, you care for the person. All have a micro focus inward. The person is the problem. Now I submit to you that some of the men and women we're talking about here have challenges in their life. No question about that. You know that and I know that. No mystery here. The question is, however, what are we going to do macroscopically in the broader arena. What does all this mean for us? Wherever we might be in the human service process, whether we're in the front end of the emergency trauma unit or out in the long term support end, what does this mean for us? And what can we start to do now to establish a direction so we can start to change this thing around a little bit?

To this end I submit to you a new way of thinking. I challenge all my friends in the acute care model to start thinking about this. What's the real problem in head injury rehabilitation? The problem is how we're going to get to a more valorized dignified approach to programs. By the time we get to community support needs, the die has been cast. The problem is that there's a lack of support to supplement and compliment the deficits. That's the real problem—a lack of support to supplement and compliment the deficits. And where's the real problem? The problem is not in the individuals by this time in the process. I mean, whatever's happened with that acute care and trauma care, in terms of saving and stabilizing lives, the microscopic emphasis that's necessary to save people, starts to give way to the problem being in the system. The way the system thinks, the way the system is structured. And what's the solution? The solution at this point is to develop supports. To start looking macroscopically. We need to stop thinking, "well the person can't think articulately anymore." Maybe they can't. But the real issue now is what can we do to support that individual now? Where should we get the money to create community supports? How should we position ourselves politically? How should we position ourselves socio-politically to do that? That's our problem, that's the question.

By this time we need to stop reading Rodger Wood. Let's stop reading Muriel Lezak. Let's stop reading Mitch Rosenthal. Let's start reading more systemic works like *Eyes on the Prize*, by Juan Williams. Let's start reading Aleksander Solzhenitsyn. Let's start reading Saul Alinsky. Let's start talking about injustice and how we can start to move the system to address those kinds of things. Now I say this not as an insult to my friends, Muriel Lezak, Mitch Rosenthal and Rodger Wood. They are fine wonderful people. They have given us a lot of information to use and I think we should use the information. But equally I think we ought to start looking at the larger system. Who should be in charge of the process? The person with the disability of course. They should be in charge! Finally, what should be our outcome? The outcome is not independent living because there's not a person in this room who's independent. We all live interdependently relating to systems. If something goes awry in your system you usually adjust with another system. None of us are an island. Maybe the energy we focus on fixing people to be independent might be a waste of time. I have a friend in Boston who has a physical disability and he told me that for years and years he went from rehab program to community re-entry program, to this program and that program. In all this effort, a major goal for him was to put his pants on independently. He said, "You know, it takes me two hours to put my pants on. I can do it to make some Physiotherapist happy but what do I really need? To make some Physiotherapist happy or to get my pants on and get out and work and get out in the community? That's what I need! So get me a personal care attendant; don't teach me to get my pants on any more. Get me somebody who can solve the problem I have, so I can get on with my life." I think that's important thinking, not for everyone and every case, but certainly in a lot of cases, I wonder, as we start to structure our community re-entry programs in head injury rehab and our long term support programs, are we thinking about this or are we developing them with a classic medical model? A lot of the programs I look at are medically oriented.

Now I suggest to you a couple of ideas that we can move from; things that are already on the books and offer a starting point for developing long term supports. The first is the definition of independent living, as identified in the Rehabilitation Act of 1973 passed in the United States of America and amended in 1978. This definition, that took a number of years to develop, offers a dynamic philosophy. It defines independent living as *“control over one’s life based on choice of acceptable options that minimize reliance and dependence on others.”* The key words here are control, acceptable options and choice. I submit this to you as a starting point. This should be scripture as we look to develop long term supports and community service for re-entry activities for folks with disabilities.

Now this notion of independent living just didn’t blossom into the clean blue air. It was built upon some very, very powerful struggles of human rights and injustices that other people have experienced. It spawns from the minority movements, the women’s movement, the movement that’s going on in South Africa right now. Civil rights, consumerism, giving the individual the power, the sovereignty to say what they want and ask for what they need and the self-help approach, where individuals who happen to have disabilities support other individuals with disabilities. These are very key parts of the independent living concept.

Another building block of independent living was the deinstitutionalization movement. I submit to you today that there’s not a person who needs to be in an institutional setting. Sure people have needs, but the magic of what people need is not in a building, ladies and gentlemen. The magic is not in a building! The magic is the human beings that are supporting and complementing the individuals. That’s magic. And part of this magic is that we’re portable. I jumped on an airplane in Pittsburgh this morning and here I am in Toronto this afternoon. We’re portable. There’s nothing magic about a building or a room or a place. What’s magic is us. Consequently, in terms of thinking about support needs, I don’t think there’s a place for institutions.

The other tenet I want to share with you is the concept of ‘Valorization’. Valorization is a French word that means giving value to something. If something is valorized it is raised in its value. This concept was promulgated by Wolf Wolfenberger in his writings. His thesis is that individuals with disabilities have been devalued, that this devaluation has created a deviancy concept. If you’re not familiar with Wolfenberger’s work, let me give you a quick capsule version. The deviancy concept is related to difference. When individuals differ, for whatever reason, they are usually perceived in a deviancy role. We’re all social animals; we want to be like each other. Yet, when something happens, when fate occurs and somehow we are perceived or are positioned as different, we get thrust into a deviancy concept. Often this deviancy concept creates a stereotypic role about that difference.

Now the best way for me to understand this concept is through my ethnic heritage. I’m Italian and my family emigrated from Italy in 1911. When they came to the United States they were different from the norm; they were deviants. They spoke a different language; they ate different foods; they had different customs and culture and so, consequently, they were put in a deviant role. This role led to stereotypes and what are the stereotypes of Italians? They talk with their hands, they’re passionate, they’re great lovers, they’re in the Mafia, they’re into negative kinds of things, you can’t trust them, they’re clannish, right? They’re short in stature but they’ve got a lot of hair on their chest and they wear those gold necklaces with a horn. If I took my tie off, you’d see mine—we all have them, we were issued them when we were born. That is stereotypic of the Italian’s, right?

And this is not just true of Italians, you can take any group. What about Irish folks and their stereotypes? You know what they are, right? I don’t have to tell you what their stereotypes are, do I? Well of course they love to drink and they love potatoes and they always want to be in charge. You know, Irishmen always want to be cops and supervisors of things; they always want to be in charge. And what about black folks? You know the stereotypes of blacks. They love watermelon and fried chicken and they all walk around with radios. In fact they get issued radios, just as Italians get issued the little horns. And they’ve got rhythm, you know, black people have rhythm.

We also know about elderly folks, we know the elderly have stereotypic roles. First off, when you turn sixty you know the first thing you do — run out and buy bingo chips. Something happens to their brains. I'd like to do a study on this. Certainly the elderly want to live in high-rises. Automatically they want to live in a high-rise because, you know, they're sixty and need to live in a high-rise. And they become terrible drivers. When you get in a traffic jam, invariably you know it's some old guy who can't see over the wheel. Elderly people!

And what about people with disabilities? Stereotypic roles of people with disabilities, to get to a more sombre kind of note. Well, we know that people with disabilities are diseased, right? They're diseased, they're sick. Let's try to think like the lay public here gang, because the challenge now is macroscopic. The challenge is community. So what does the community think about people with disabilities? Well, obviously, they have a disease, they have something that's weird about them and it might be catchable. You know, I teach a class at the University of Pittsburgh and each term I assign the students to go out on campus in wheelchairs for a sensitivity exercise. Two things really amaze them. One is how physically gruelling it is to go around the campus area with a wheelchair. But, secondly, and probably more important to them, is the social isolation and the negativism that occurs. They get on an elevator and people move aside like they are going to catch something. So the lay public perceives the person with a disability as diseased.

They are also an object of pity. We know that they are pitied; we just look at the literature. Books like "Flowers for Algernon", "The Hunchback of Notre Dame"; movies like "Charlie, Dominic and Eugene". Again about pity. We know that telethons are all about pity. In the telethon, the whole idea is to rip your heart out and make you feel so bad that you send money. That's what they're about. Now I work for United Cerebral Palsy in the United States and we run a telethon. Pity is a big part of it. It's doing exactly what we don't want to do. With telethons we're on our knees. Benevolence, right? We're not getting any support from the government so let's get on our knees. Take the crumbs, and let's sell our souls to get by.

Another key stereotype is the object of ridicule. We know there are people with disabilities who are the butt of jokes. I have a classic story on ridicule. You know I like to tell a lot of stories. The reason I do that is because universities know by doing studies, and businesses know by doing reports, but communities know and people know through stories. Let's forget the reports, and let's forget the data and let's talk about human beings and stories. The story that I have about ridicule is related to a friend of mine whose name is Joe Migallucci. Of course, in our community everyone called him Jo-Jo. Like most disabled folks, he never got out of the permanent childhood stereotype. He was always perceived as a kid because he had a disability. So one day Jo-Jo succumbed to the ultimate ridicule and joke. On this day he was delivering his newspapers. You know of course that's what they do, retarded people, they deliver papers. So Jo-Jo was out delivering papers and some guys in a bar in the neighbourhood said, "Hey Jo-Jo, come on, take a drink for your job". Jo-Jo came in and they said, "Here, take this" and they poured the drink (they had it mixed, one half chlorox, the other half alcohol). Jo-Jo drank it straight down, collapsed and died. Now the sorrow of this story is certainly not just Jo-Jo's death but the fact that not one person was brought to trial because Jo-Jo was worthless anyway. His death wasn't perceived to be any bad news in our community. The object of ridicule, a permanent child, the menace to society, the subhuman, the individual being less than human. These are all stereotypes that persons with disabilities face. These are crass examples but I didn't make this stuff up. This comes from the literature. These things have been reviewed and studied. Wolf Wolfenberger spends a lot of energy on this.

Now the other tenet of the valorization theory is that when somebody is kept in a role or stereotype so long, sooner or later they start to behave that way. Role expectation leads to role behaviour. If somebody is treated a certain way for a long period of time, if they get the message from day one that they are a certain person because

of their difference, then sooner or later that stereotype is going to prevail. It's a self-fulfilling prophesy type of thing.

The story I like to share about this one, that personally happened to me, occurred when I was going to the eighth grade in school. It was my first day of class and, having a big extended family (you know Italians are prolific and wild), many of my cousins had come before me. So it was my first day of class in the eighth grade and Mrs. Glassbrenner was the teacher, a German lady. Even though we haven't talked about Germans today, I'll let you conjure up every bizarre stereotype that you have ever thought about German people and that was Mrs. Glassbrenner. So there we were, the first day, and she was looking at the class roster and she says, "Get up here!" So now I'm shaking in my boots, and she said, "Sit right here! Last year I had your cousin Gerry and he was the worst student I ever had in my life and you Condoluci are not going to do this to me anymore." Now I'm stereotyped as a troublemaker. So Mrs. Glassbrenner turns around to write something on the wall and, as she turns around, I gave her the Italian salute (obscene arm gesture). I made Gerry look like an angel. I had a really bad year getting in all kinds of trouble. As a matter of fact, the principal came to my family's home and said "Mr. Condoluci, don't invest any money in this kid; send him to become a cement man. You know, that's what that kid can do. He's a troublemaker, he's a problem." If they could see me here today—I'm not a troublemaker! I'm not going to challenge anything! Thank-you Mrs. Glassbrenner!

Anyway, let's quit the stories now and focus on where we go from here. How do we put all this together? I'm going to try to conclude this by starting with one of my favourite subjects — passion. I think the quote by Disraeli, "Man isn't truly great until he acts from passion," is absolutely essential. We're not really great until we get angry, until we get energized, until we get hot. That's when we do great things when we get angry. And, when our passions are ignited, we start to think about the injustice of men and women having to go to sheltered workshops and put screws in bags, that's injustice we start to think about men and women who don't have opportunities for social and intimate relationships. That's passionate stuff to get us angry and get us started. And passion leads to advocacy.

I think advocacy is comprised of four simple things. It's a passion about something, it's anger, it's energy, and it's a gut feeling. You don't have to stand up on a stage like this and yell and scream and talk with your hands to be passionate. Some of the most passionate and powerful advocates I know are soft-spoken, quiet people who get the job done. Passion leads to a position on something. Position is, in fact, the convictions that we believe in. Position requires a presence and the whole effort takes perseverance.

Let me share with you some convictions that I think are really important, in terms of playing out the empowerment model. One of them is relationship building to natural supports. Did you know that, for most people with disabilities, primary friendship networks are usually paid staff people? That's a real tragedy. To address this we need to link people to bridge build. In our program in Pittsburgh, I was attempting to bridge build with a fellow and I connected this guy up with a neighbour who was interested in him as a human being. So I made the connection and then I left. That night, my friend with a disability called me and said, "Al, what was this guy about? Was he one of your staff?" I said, "No". He said, "Is he a volunteer?" I said, "No". "Is he a student getting some degree credits for this?" I said, "No, he's just an average guy who wants to be your friend". He said, "My God, he must be lonelier than me". Now we're laughing about this, but think about it. This man could not even perceive himself valuable enough to have somebody be his friend naturally. It had to be some contrived sort of thing. That's incredible loneliness ladies and gentlemen.

Community involvement. Active participation. You know, the last couple of years we've moved and facilitated people going into communities but have we really helped these people become of their communities? There's a

difference here. Being just in communities rather than of communities are two very, very different things. You know someone can be just as isolated in the community as they can be in some mountain retreat. Active participation, non-intrusive interventions, privacy of personal space, these are things folks with disabilities want, you want and I want. There's nothing novel and strange here. Real choices.

Now, the way we go about doing this is to get impassioned about those choices and visions and we say "how do we now start to position ourselves as an organization, or as a human service specialist to try to address this change?" Now I submit and suggest to you that there are a lot of positions that we can take on these issues. One of them is making reform and long term supports for people who are government supported. In our country only 17% of all those injured every year have third party funding to follow. That's a hell of a lot of people who have no funding to support them at all. So, for us, our position is to get long term supports available and accessible to individuals with disabilities who have no third party support.

But no position is really worth its salt unless we're out there presenting this material and being present in the minds of policy makers, public and private, and in the minds of the insurance industry that doesn't understand these concepts, and in the minds of the government officials who don't understand these needs. So the concept here is to be present. And presence can be in either letters, or a visit, or a rally, or newspaper articles. You know there are a variety of ways we can get the position across but we've got to be present with this material.

And then finally, and probably most importantly, is perseverance. Soldiers of other minority struggles know that these kinds of changes in thinking and attitude are a very long hard battle. Things don't change overnight. Just look at the civil rights movement across North America. We are seeing unbelievable episodes of racism still, twenty-five, thirty years later, still.

So this is a long battle folks. This is a long haul. We've got to be perseverant. We've got to be energized. We've also got to recognize when we're selling out. The one problem with time-lagged advocacy is that there is a propensity to sell out. Advocates kind of get tired and say, "Let's go with what the other side offers because, what the hell, we're not going to get what we really wanted anyway, and we're tired and this is better than nothing." Well I agree that something is better than nothing, but I also agree that when we do those kinds of things we've got to remember that we sell out and sometimes we lose the energy for the more appropriate alternative.

So it is a long battle. *To create viable community supports is not easy work. But it is right. It is right that people don't get put away just because supports don't exist. All people, I don't care how severe, should and could benefit from community alternatives.* This is our battle. This is our mission. This is my vision.

Folks, I appreciate the opportunity to come before you today. I know I have been direct, and maybe confrontive, but my intent is hopefully noble. All of us, no matter what our clinical speciality or interest, need to work together to create the best outcomes, the best tomorrows, the best future.

We are caring people. We are the best and the brightest. If we can't make it happen, no one can. Let's get out there and make it work.

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