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*Self-Determination Through the Prism of Community*

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***The views expressed are solely those of the Author and do not necessarily reflect those of SAMHSA/CMHS.***

I am delighted to be with you here today and to share this occasion with some of my friends and associates—Joe Rogers, Judie Chamberlain and David Oaks. I think that all of us are rightly concerned with the topic of self-determination with respect to mental health consumers and survivors. Indeed it is now fitting perhaps that I address this issue from a broader and more universal perspective and acknowledge that the concept of self-determination is not viewed as an isolated concern for the established voices now in the consumer movement. I am pleased to be here in this forum with such dedicated individuals and welcome the opportunity to give my insights on this issue of self-direction, personal power, choice and well being and to make this discussion even enjoyable for both the initiated and those less so. Thank you Dr. Cook for your generous invitation.

I hope that as I begin to describe an alternative definition of self-direction that you will bear in mind the momentous struggle of black Americans and women, who invoked the language and principles of self-determination to defuse the strange logic of segregation and repression—and countered those who would insist on a strange social policy that encouraged a separate but equal doctrine that was not overturned until the Brown Decision of 1954 that held that separate but equal educational facilities are

inherently unequal. Patterns of segregation still persist however. These courageous men and women succeeded I believe in speaking truth to power—holding to the proposition that segregation on the basis of race violated the concept of equal citizenship in our evolving democratic form of government. They understood that self-determination was a moral and political value that transcended race and class—and understood moreover that self-determination was a principle that could unify an otherwise fractious community. So from marches of protests to sit-ins at lunch counters, blacks and their supporters tested the conscience of America—and won, but the struggle as you well know is not over. While there has been much progress to achieve equality for all, we know that in our midst others have not been welcomed at the table of brotherhood.

Let us acknowledge at the outset that justice presupposes a certain capacity for order and rule—and that this capacity extends to individuals, communities and nations. Justice presupposes in this context a healthy respect for law and its execution. It is within this mindset that I discuss self-determination as an expression of sovereignty as both a right and a responsibility to each other and among others as well. Properly understood community likewise presupposes an adherence to both order and the recognition that an individual's rights and responsibility are co-extensive with those of others. It is through the prism of community that we give expression to individual liberty—both in terms of defining the limits of our communal life together and the means by which we choose to express it. This is a constant struggle—one worth pursuing I believe. Justice presupposes a certain moral capacity to accept judgments that may conflict with personal norms but that on further reflection advances the freedom of everyone. Let there be no mistake some individuals, communities—and even nations, do not accept this supposition and as a consequence their capacity for justice is vacuous—and their claims against this fundamental freedom are therefore suspect and not compelling. For us the capacity to govern and direct our own lives is consistent with our democratic ethos and charters of freedom. Self-determination is our link with a noble tradition of individual respect and communal health and happiness. Self-determination recognizes a rule of reciprocity. Considering that justice presupposes the moral necessity of law in any given society, we posit that laws binds us to each other as a persuasive matter and as an obligation to our covenant with justice and that this assumes that our claims to be treated justly ring with meaning among our neighbors both here and elsewhere. We are obligated to respect the rights of everyone lest our own be not so richly regarded.

Those with disabilities are now facing a similar fight for inclusion and respect, while the atmosphere is now poisoned with a type of thinking that says that we have done enough to foster justice for all. While the recent Olmstead Decision gives us as advocates some measure of hope, other decisions like Garrett give us reason to pause as

we contemplate what a society would like if constitutional guarantees of freedom were somehow suddenly repressed. Self-determination, I argue is a way for us to strategize against unfavorable opinions—and is a way for us to achieve true community without over-polarizing it as race and gender might. I would advance the argument that the protesters of the 1950s and ‘60s understood the value of the moral center and recognized that the costs of freedom need not be dollarized— and even if it were so dollarized they understood that the price of inequality was too high and strained the meaning of justice and knew that our covenant with democracy would be seriously undermined. But some, I am sorry to say, understand only the price of justice and not its resultant value and benefit. It is my contention that justice cannot be operated on the cheap and that justice ought not forever be subject to a rough cost-benefit review. Some things are just right in and of themselves—and that people most assuredly have rights beyond what the process gives them or deems appropriate is yet another self-evident truth. We reject the notion that our very *being* ought to give rise to *insult*. For discrimination and stigma is just that—insults on the human character, an assault on *difference*. And we should resist the temptation to believe that any one theory—whether it be “recovery,” “empowerment,” or even “self-determination,” embodies all truth regarding the human personality, or that any one word or phrase can adequately summarize our struggle, our hopes and dreams.

Self-direction gives us the opportunity to think afresh about justice in our society. The writers in the Historians’ and Scholars’ Brief submitted in the case of *The University of Alabama v. Garrett* wrote: Persons with a broad range of disabilities—cognitive, motor, sensory, and psychiatric—have been the victims of intentional and irrational state-sponsored discrimination and exclusion from the basic rights of citizenship in every aspect of public and private life, including employment, housing, the judicial system, marriage, parenting and education. Congress was aware of these centuries of discrimination when it enacted the ADA. To sustain the momentum of the movement and realizing the dream of personal power and choice, we must forever remain watchful of the present and cognizant of the past. Self-determination however is not only grounded in law but is also grounded in our intuitive sense of fairness and proportion—and we must therefore align our voices in speaking truth to each other, and speaking a truth to power. I believe that self-direction can help sustain community and is less polarizing in its aims and purposes and effects. By self-determination, I guess we mean the process and life course of achieving empowerment over time with regard to augmenting our equality and autonomy in a society where pluralism is often divided. By self-determination, I guess we mean the process by where a person’s choices are honored and respected. By self-determination, I also suppose we mean something more than just the mere realization of our own narrow desires. But to appreciate the concept we must address the complexity of the idea in the context of our communal life together. By self-

determination we not only mean the maximization of our own good fortunes, but also the maximization of a type of power beyond the narrow definition of personal rights and privileges. When we recognize that we share a life in common, we also mean to say that we share a concept of full liberty while understanding of course, that no one is really free until we are all accorded equal dignity and respect. When we speak of self-determination here today, I take it to mean that we are all involved in a common purpose to maximize individual self-worth as a principle of our collective politics. We do not mean to suggest that our purpose is totally focused on the idiosyncratic of the personal, but we focus necessarily on communities across the land, and for me, particularly communities of color—recognizing of course that all of our lives intersect on this highway of human existence. By self-determination we are not just not talking about the freedom of one person or even one community. My understanding is that the “consumer” in a market driven society is sovereign, and if such is the case in our context, then ought not the concept of self-determination be considered in the light of this legitimate sovereignty—a thought that recognizes the full freedom of the individual actor in pursuit of her goals and should not this thought apply to consumers in the mental health community? Or are we to suppose that consumer sovereignty only has cache in a market-like context. In any case, consumer preferences if honored in such a context, should also have legitimacy in other contexts even if they are deemed not to be market-oriented. I propose that consumer sovereignty is consistent with a notion of personal power and self-direction and choice especially in this forum and in determining how we choose to govern our lives in a sociopolitical sense. Honoring preferences is not only a good business strategy and customer-focused and friendly, it is also a good strategy for how we access treatment and determine its effectiveness with respect to our values as individuals and as societies. However, I would also propose that self-determination properly considered is something more than the mere mimicking of economic transactions. It is the linchpin of our sense of self in community life. Paternalism then is the antithesis of this type of sovereignty. And unless there is any doubt, let us be frank in acknowledging that sovereignty of this kind is both a right and a responsibility not only between states but also between and among individuals.

My view of the world is that as long as one people are shackled so too are all other people. So for me, self-determination as a political principle cannot be isolated as the sole preserve of one group, one community, or one nation. The yearning to be free and to choose and self-direct life is of a more universal nature and dimension. Those of us in the mental health community rightly understand self-determination as a concept that bridges an otherwise fractious community. I propose the radical idea that self-determination means more than one individual realizing his/her purpose. Self-determination is realized when all are made capable to enjoy life in communities of their

choice, understanding that good and wholesome choices are the result of living in environment where personal dignity and respect are treated as essential elements of a good life. We really achieve self-determination when we emancipate ourselves from the familiar to the more general, from the particular to the more universal. It is when we recognize that differences do exist between us and other communities, but on further reflection see common purpose when we recognize too that there are also similarities that bind in a common enterprise on this highway of life.

To achieve self-determination we must free ourselves from chain of the familiar and enter a process where we welcome change and the diversity that is a result of it. We celebrate the pleasures of pluralism and acknowledge its perils. It does not mean that we have arrived merely because we are satisfied with our successes and strengths, but self-determination across the board means that we all travel together—not separated by the politics of class, race and gender. To pursue an agenda of inclusiveness, we must prepare ourselves—as you have done today, to engage with broader movements, publics, groups and constituencies. When the self is liberated from the familiar, there is the potential to realize a more encompassing vision of choice for others as well as for self. We do not occupy this space, this island, this highway, alone. There are many more people on the road—some black, some Hispanic, some Native to this world, some disabled, some aging, some very young, others who too are disconnected while seemingly otherwise. We believe that in achieving self-determination for the individual we also lift the life of the community, that village, that hamlet, that otherwise forgotten town square. There is from this perspective no such thing as the completely insular community or purely self-regarding conduct and consequences. “A: surely affects, B.” My actions in or out of community affect everyone even from a great distance. Our world and our actions in affect even those beyond our own borders and wherever we may be domiciled for the moment. We do not subscribe to the belief that biology is destiny—nor do we deny that diagnosis carries some consequence affecting the life course of the person. We accept the premise that apparent self-regarding conduct has other-regarding consequences—that a *diagnosis* of illness affects the individual, his community, his family and other important relationships.

The principle of self-determination is thus a universal one—one that affects the village and the people on the mountain, on the corner of the street or on the edge of a bar stool. Self-determination presupposes a certain modicum of freedom, free will and personal liberty and desire. But what happens when a whole class of persons is denied this freedom to engage in the world—to be a part of a greater whole, to feel connected to others in spite of difference. Understood self-determination is about choice and opportunity to make a difference in one life for sure but to also make a difference—a sea

change, in the lives of others. While the personal may indeed be a political, it is the personal that transcends the merely political and transforms the whole community in the interest of all who desire to live in free states. Self-determination involves an awareness of the other and a recognition of the singular at the same time. While I fight to be free today, I also fight for the freedom of my daughter or brother tomorrow—or a stranger today. Self-determination carries weight beyond merely satisfying the particular and transforms communities of all kinds. I propose that self-determination is both a communal and kinship factor—linking villages and communities across space and time, not just isolated individuals. Wouldn't it be interesting if the idea of self-determination in the mental health context would mean, that consumers would have the right and the option to self-direct their care with all the financial support that would allow for that to happen. Something similar to “self-directed” care is already successfully underway in the developmental disabilities communities. Perhaps, we can find a way to emulate this innovative practice wherein consumers can hire and fire their support staff and have greater autonomy and choice with respect to the services they themselves determine to be both necessary and appropriate. Without cash and its equivalent self-direction as a policy matter remains vacuous indeed. Economic integration within the community is a key to recovery and consistent with democratic notions of inclusion and respect. Perhaps, what we are advocating for is something like “life-coaching” as opposed to traditional *therapy*.

The struggle for human equality in communities of color has been of particular significance. The abolitionist movements, the civil rights movement, were movements that involved larger principles than just the satisfaction of the singular. Indeed these movements were broad attacks on systems of hatred of all kinds. These movements may shed some light on contemporary movements for self-determination and recovery. We see in these movements people who were concerned with issues of freedom, justice and equality generally while meshing and linking the philosophy across borders of sovereign states—a truly universal message of freedom – whether it be for freedom here in America, Latin America or South Africa or even Bosnia. Once again we see a picture where the particular affected the general, and where the specific was painted a canvass of others in action, not just for the personal benefit of a few. In order to emancipate the self from whatever bondage, we must embrace more than just the familiar. We must draw closer together for sure—and make room for many newer, fresher voices—not at the expense of dismissing the older forms of protests, but to build on that previous strength in the interests of further populating the highway of change. We are cognizant of the fact that mental health treatment in some societies is nothing more than “re-education” of an ideological nature. Are we sure that such is not the case here? Understanding the human rights dimensions of treatment modalities, we are gravely concerned with how pharmaceutical companies exercise research in other nations.

I remember sometime ago reading a short story by Langston Hughes:

Someone asked what does the Negro want?

What do these women want?

What do they want?

Or:

Want they ever be satisfied?

Isn't this a great country?

Why do they whine so much?

Or:

Can't we just get along?

Such questions perplex me on one hand and amuse me on the other. Of course, what we want are the same things you want—a place to call home, a job that is fulfilling, a dream to be fairly pursued, a justice that is unbiased, a future for our children and their children, a freedom from poverty, sickness and isolation, to live in a nation that will hold truth to the highest degree of respect, to live and grow in concert with our talents and abilities, and to live amongst neighbors who respect certain rights of privacy while in community. We recognize of course that to be sufficiently engaged in community life is done through the aegis of consent and not through the artifice of fiat and command no matter how nobly characterized.

It is often said that “not having” is a reason for “wanting.” And what we have not had in this land—indeed, in this world, is the right to pursue our dreams without fear and

intimidation. We embrace self-determination because we do in fact understand freedom, even though we may have not been blessed abundantly by it. We understand why the caged bird sings. We understand the loss of dignity in a locked ward. Like Rousseau we understand that men and women are everywhere in chains—whether in physical or chemical restraints today. We understand the loss of parity in insurance plans and programs. We understand ethnic cleansing in Bosnia and Rwanda—and the history and consequences of mental hygiene here. We understand discrimination and stigma and prejudice. Nevertheless we pursue lives of quality and substance even when we are denied entry into the marketplace or when neighbors next door say not in my backyard. We embrace peace even though peace had not been too friendly a visitor in our homes and neighborhoods. We understand the incongruity of prisons and detention centers as places for mental health treatment. We understand the psychology of denial. We understand that treatment alone is not a panacea for our ills. And we understand that this society has an unhealthy definition of what constitutes health. We understand that health does not mean the cessation of all ailments—the cessation of all disease and the eradication of all harm. In this context we understand that housing is a health concern; that employment is a health concern; that poverty itself is a health concern. We do not advance health when just treating a *diagnosis*. And we understand that diagnosis ought not mean a destination point. Rather diagnosis ought to be viewed as a moment in time, an interruption in the life course. Good health does not refer to merely treating symptoms of illness. Rather health refers to living a life well—in all of its dimensions, spiritual, social, cultural and economic. We understand that therapy is at its best when characterized by partnership, sharing and trust and mutuality. We ask you to remember that where consent is thus given, it can thusly be taken back. We reject the inherent paternalism inherent in most medical models. We dare—shall I say deign to believe that recovery is possible and desirable. We understand that choices and their healthy consequences must be cultivated and cannot be left to good intentions and not without wholesale modifications of traditional therapeutic interventions. Above all, we understand that choices make for better outcomes.

Last but not least, we embrace a system that is culturally competent as a way to achieve quality outcomes and diagnoses, not disconnected from a person's social and cultural context and milieu. We believe that people are essentially a bundle of characteristics, and that a diagnosis of bipolar illness, schizophrenia are not the only markers and identifiers of a fully integrated human being. We know that discharge planning is more honored in the breach than in the practice. We understand the benefits and costs of medications and the dangers of over-medication and the “McDrug” culture we live in. We know that there are those who champion profits over care—economies

over basic human qualities. We understand the intervening grace of choice on these and other matters. We understand that ills affect both systems and individuals. Thus we know that individuals can recover and that our systems are likewise capable of recovery too. We understand that stabilization and maintenance should not be the “be all and end all” of all systems—psychosocial, rehabilitative or otherwise. In noting these things, we view these realities as challenges not as problems to be catalogued and managed, but as opportunities for sustained improvement. We remain skeptical about a type of consumer society that values brand loyalty to products and labels rather than to each other. We find it interesting to say the least that community-based organizations somehow know what is in the best interest of their clients—a power of divination that we now deny to most courts of law, and how such agencies show contempt for choice under the guise of authentic caring. We believe consistent with self-direction that people can determine in most circumstances their needs, and that it our obligation to help not supplant them in this effort. Whereas many jurisdictions are now redesigning and reconfiguring their mental health systems, dare we suggest that reconfiguring their thought patterns regarding consumers is in need of substantial repair as well? Is it not high-handed, arrogant and presumptuous to act otherwise? We know that there are still thousands more in institutional settings—including nursing homes; and we know that there are still thousands more incarcerated in jails and prisons. Is not then understandable why some people do not seek treatment because they ground their fear in the fact that those needing help will either be locked up or carried away. I recall a statement by Dr. Alvin Poussaint that poor people fear two types of people—the police officer and the psychiatrist. Why? Because they—those in the core of our cities, know that their freedom is at risk with such health care providers and practitioners. Do not ridicule us for remembering the horrors of the Tuskegee Experiment. Our mistrust of systems in general is justified. Doubt is a legitimate factor in our existence. We remember that black men were used as guinea pigs and that treatments for syphilis were methodically withheld. The ecology of care in our society needs to be improved—building a system of care and trust will be monumentally difficult, but it is an imperative, and conferences of this kind help in this regard. We know that we do not have to be as separate as the fingers in ushering in a New Freedom, but the lessons learned from the Old Freedom are not without consequence today. There is doubt as to whether we can engage with one another—and the only way that such doubt can be buried is if truth in the past is necessarily resurrected. As one writer said: “What I did not know then, I did not know, but now that I know a little bit more, I can do a little bit better.” We ask you not to discount our sense of memory, not to discount our fullness as human beings. We ask you to recognize our pains at forgiving the past. We believe that understood non-compliance with any type of treatment regime or protocol is consistent with a recovery paradigm.

Our distrust should not be discounted as the mere manifestation of an illness, but as something grounded in truth—a truth to be acknowledged and not dismissed out of hand.

I have gone on at length to suggest that self-determination is something more than realizing personal awareness and personal power—for communities of color, self-determination is the yet to be realized promise; the yet to be fulfilled reality, another dream deferred. To be without choice, either because of accident of birth or unwise social policy is a stain on the very unified pluralism that is evident here today. What does the person of color want, a type of self-direction, a self-determination that uplifts all, that benefits all, that frees us, that is uplifting to the heart and to the soul. We understand that a climate—indeed, a psychology of choice must be cultivated as with tolerance of difference, and that these things cannot be left to develop through accident, luck and chance. To create the beloved community, we must seriously pursue lives of meaning and declare self-direction as a self-evident truth. We know that self-determination is something more than self-regarding practices.

As the poet Margaret Walker Alexander writes:

I dream of a world that will hold all the people—all the Adams and Eves, and their countless generations. How sad it is to be thus misunderstood and marginalized. How sad not to be remembered for the unique gifts we bring to the world. How sad to be forgotten. How sad to be looked down upon as small and different when considered black, female or disabled. Self-determination properly or alternatively considered involves us in a reach toward the “other” in concert with the singular or the purely individualistic. It is a call to action—across communities of color, gender and class. Self-determination emancipates and invigorates the whole society as well. When all are enabled to realize personal satisfaction, the whole society—from the hamlet, the village, the town square are all remarkably transformed and empowered. We believe in a self-direction that manifests itself as a “pluralized, I” and as an inclusive “We,”—as in ‘We the People.’ An African proverb reminds us: “I am because you are, and you are, because we are.” We as consumers and advocates recognize that there is no necessary incongruity in pursuing both the singular and the plural and that true communities exist to foster both—to champion and celebrate both the individual in pursuit of his/her goals and to realize simultaneously the beauty of creation in community. Self-determination—choice—connects us to each other and our world. And that our personhood is enhanced through recognizing the same in others—that our claims on the society reflect the knowledge and the belief that our rights are co-extensive with others in our communal

niche. Maybe we will no longer have to be as separate as the fingers in all things social—and maybe we can be as one as the hand in all things economic and essential to mutual progress. My dream is that just maybe we can build a world—a community where we are united in our differences and not made fractious because of them.

*And what a beautiful world it could be  
For you and me  
And for all*