White, W. (2009). A commentary on "consumer": Language, stigma and recovery representations. Posted at <u>www.facesandvoicesofrecovery.org</u>

A Commentary on "Consumer" Language, Stigma, and Recovery Representation

William L. White

The difference between the right word and the almost right word is the difference between lightning and the lightning bug.—Mark Twain

At every word a reputation dies.—Alexander Pope

By our silence, we let others define us.—Susan Rook (Missouri Recovery Network campaign slogan)

Addiction treatment organizations and a variety of policy-making, planning, and funding authorities are changing their historical focus on acute biopsychosocial stabilization to a broader vision of sustained long-term recovery for individuals and families. This shift can be seen in widespread discussions and practices that embrace "recovery management" and "recovery-oriented systems of care." This change in organizing concepts and service practices will not be possible without the meaningful involvement of individuals and families in or seeking recovery in the planning and decision-making processes.

The word "consumer" is cropping up more frequently, with references to "our consumers," "consumer representation," "consumer councils," and "consumer-based" or "consumer-directed" services. This latest term joins a long list of terms—patients, clients, service users/recipients/participants, alumni—that have described people needing, receiving, or completing addiction treatment and recovery support services.

Historically, language applied to and chosen by historically disenfranchised groups evolves over time. People who were recovering from severe mental illness began their own recovery revolution in the 1970s and 1980s and chose to self-designate themselves as "consumers" and "survivors" as a less stigmatizing alternative to "mental patient." The surge in "consumer" language was a positive development within the history of the mental health recovery advocacy movement—one that at the time was experienced as personally empowering. It is likely that this language will continue to evolve as the mental health recovery advocacy movement continues to evolve.

With the growing integration of addiction treatment and mental health treatment services, the introduction of new medications for the treatment of addiction, and expanded efforts to include coverage for addiction treatment and recovery support services as part of comprehensive health care reform, the use of the word "consumer" is gaining prominence within the addiction treatment and recovery support communities. This brief essay describes why this "consumer" terminology is counterproductive and suggests other ways to describe the critical role that people seeking or in long-term recovery, their families, and friends play in the design, delivery, and evaluation of addiction treatment and recovery support services.

Rejecting the "Consumer" Designation

There are nine reasons to reject the spread of "consumer" language when talking about addiction treatment and recovery support services.

1. <u>The term "consumer" is ill-defined and as such, may create further</u> <u>misunderstanding by the general public and policymakers about people</u> <u>experiencing addiction or who are in long-term addiction recovery</u>. There is no generally understood meaning of what exactly is being consumed, and members of the public may well think the term refers to people who continue to consume excessive amounts of alcohol and/or drugs.

"The 'consumer' language suggests that the person in treatment is a social 'taker,' that they suck up community resources and give nothing in return—a parasitic relationship to others."¹

People in active addiction are often involved in a parasitic process of using (in the manipulative sense) family, friends, and community resources to sustain their alcohol and drug use. "Consumer" is a more apt description of someone in active addiction than of a person in long-term recovery. Furthermore, the most cursory search of "consumer" on the internet reveals meanings that include a person who drinks alcohol to excess (See http://www.thefreedictionary.com/consumer). A person in recovery is more aptly described as a person who ceases being a consumer.

2. <u>The term "consumer" fails to provide an alternative identity for persons</u> <u>attempting to disengage from alcohol/drug-saturated lifestyles and subcultures</u>.

Addiction treatment can be a transitional bridge from a culture of addiction to a culture of recovery or a revolving door within a person's active addiction career. The "consumer" identity tends to reinforce the latter; focusing on the repeated "consumption" of services as well as the "consumption" of alcohol and other drugs. "Person in recovery," in contrast, builds a new identity for an individual moving forward to a new life. "Consumer" defines a person in terms of a part of the self while ignoring the whole. Participating in addiction treatment is an activity, not who a person is.

The term "consumer" had value at a particular point in time for persons recovering from mental illness. New language that had value within a particular historical context can become old language and stand as an obstacle to progress as contexts change. We need a different term to describe people seeking and in long-term recovery from addiction and people who participate in addiction treatment as part of that long-term

¹ Jason Schwartz, Personal Communication, June 12, 2009.

journey. Does that mean that any alternative language we embrace today may need to be given up in the future? We need to be open to that possibility.

3. <u>The term "consumer" ties an individual's identity to a service delivery system, be</u> <u>it a treatment provider or a physician prescribing medications, and can be</u>

paternalistic and disempowering. There are words other than "consumer" that can be used to describe a relationship between a person receiving professional care and the caregiver. For example, in the HIV/AIDS community, people who receive medications from a physician often describe themselves as patients when talking about their relationship with their doctor. Similarly, many people using medications in their recovery describe themselves as a "person in long-term recovery using medication," as a "patient" when describing their relationship with their physician, or as a "client" when describing their relationship with a clinic.

The problem is that when "consumer" is juxtaposed against "professional" or "provider," as it often is, "consumer" conveys a person of less value and authority and implies that the individual has value only to the extent to which they consume professional services or products. This juxtaposition further creates the delusion that the "provider" is whole/well and the consumer is "broken/sick." Both are dehumanized by this process, with one denied of weakness and the other denied of strength. The "consumer" designation reflects a hierarchical relational model that rests on twin propositions: 1) "the professional knows best" and 2) the role of the "patient/consumer is to listen and comply."

"Consumer" also defines a person in terms of his or her problems. It relegates the person to being one, albeit critical, component of a system of care, rather than as the driver of that care and the person around whom all care is to be organized so that the person is able to get well. There is nothing in the term that conveys autonomy (or even healthy interdependence), competence, responsibility, or describes the assets that the person brings to others and the community. "Consumer" does not convey the status of, or hope for, recovery and seems alien when linked to words like liberation, journey, transformation, Higher Power, redemption, spirituality, and service, to name just a few of the words and concepts that are associated with recovery. If we need a name, then let's use words that convey wholeness and wellness, words like "citizen," "person in long-term recovery," or "person seeking recovery."

4. <u>Using the term "consumer" to convey the involvement of people in recovery and</u> <u>their families in advisement or decision-making roles narrowly restricts the pool of</u> <u>people considered for such participation</u>. For example, the term "consumer" would not include individuals/families in need of recovery who have never sought professional help, individuals who did not complete and may have had a "bad" experience in treatment, and individuals and families who achieve long-term recovery without the aid of professional treatment. Referring to such people as "consumers" (of addiction treatment services) is simply inaccurate. Individuals in treatment constitute only a small, unrepresentative sample of those who have experienced and/or have resolved alcohol and other drug problems. Too often, "consumer" represents an even smaller sample: individuals who have successfully "graduated" from treatment and, out of deep gratitude for their personal recovery, can offer testimony to a particular program's effectiveness.

"Consumer" councils that guide federal, state, or local recovery-focused initiatives must include a wide range of voices as part of the advisory process. The term "consumer" does not adequately describe the scope of needed representative. Voices must be heard who represent diverse levels of problem severity/complexity, recovery capital, and pathways and styles of long-term recovery. The homogenous designation "consumer" ignores the distinct cultural histories and the enormous diversity of needs and circumstances people bring to the experiences of recovery initiation and recovery maintenance.

5. <u>The "consumer" designation inadvertently serves as a mechanism of "outing."</u> To routinely introduce someone as a "consumer representative" or a member of "our consumer council" discloses the person's status as a former treatment recipient or person in recovery and places the institution rather than the individual in control of when, where, to whom, and under what circumstances his or her recovery status is disclosed. For professional treatment institutions, such communications often constitute an inadvertent breach of ethics (confidentiality) and etiquette (respect, privacy, discretion). For the people serving in this role, the "consumer representative" designation diminishes and restricts how they are perceived by others and how they perceive themselves.</u>

6. <u>Terms such as "consumer," "client," "patient," and "previously incarcerated</u> person (PIP)" are inappropriate in the context of peer-based recovery support

services. These terms imply a hierarchical service relationship model that is incongruent with peer-based recovery support. For example, when a recovery coach commented to a treatment professional that they did not refer to the people they served as "clients" or "consumers," the professional asked, "Well then, what do you call them?" The simple response was, "Collectively, we call them people; individually, we call them by their names." This response indicates a different relationship—not only one of mutual respect, but one that embraces the reciprocity that is at the core of peer recovery support relationships. The term "consumer" reflects the role dichotomy of helper (a producer of services) and helpee (a user of services); in the world of peer recovery support services, each person both gives and receives.

As more people return to communities from prison in search of sustained recovery, new acronyms are popping up. Unfortunately, these names and acronyms continue to objectify and turn individuals into an aggregate object, e.g., previously incarcerated persons (PIPs) and formerly incarcerated persons (FIPs). Such names and acronyms have no place in the world of addiction treatment and recovery support services. 7. Embracing this term in the addiction treatment and addiction recovery support arenas may amplify stigma by pairing the stigma already attached to addiction with the stigma attached to mental illness. Given the dominance of the term "consumer" within the mental health field over the past two decades and the existing Consumer Advisory Councils for people with mental illness in each state, "consumer" has become a code word for mental illness. Joint use of "consumer" by the two fields may compound social stigma by inadvertently signaling that all "consumers" have histories of <u>both</u> mental illness and alcohol/drug addiction.

The use of "consumer," because of its association with the mental health field, may also reinforce the view that addiction is a symptom of mental illness and not a primary disorder. It is critical that people with co-occurring addiction and mental illness receive the specialized and integrated services that they need to achieve long-term recovery. However, it is imperative that addiction is recognized and treated as a primary disorder.

8. <u>The term "consumer" used in the context of addiction treatment mistakenly</u> <u>conveys the image of a seller-buyer relationship, with an informed customer having</u> <u>substantial autonomy, power, and choice and rights of redress if the product or</u> <u>service is faulty</u>. This is not an accurate depiction of most persons entering addiction treatment in the United States today. The growing percentages of people entering treatment via external coercion, the substantial power differential between addiction professionals and their "patients," the limited choices available to those forced into treatment, the lack of knowledge about those choices, the absence of lobbyists and advocacy organizations representing individuals and families in addiction treatment, and the lack of any significant mechanisms of redress for ineffective or harmful treatment are all obscured by referring to those entering addiction treatment as "consumers."² The term "consumer" is used in few other contexts in which choice and redress are so limited.

9. <u>The term "consumer" has a commercial/marketing/sales connotation that</u> <u>overemphasizes the business aspects of addiction treatment and is particularly ill-</u> <u>suited for people involved in volunteer, peer-based recovery support services</u> <u>provided by recovery community organizations</u>. The term "consumer," perhaps not unexpectedly, came into prominence in the roaring "greed is good" days of the 1980s when addiction treatment organizations were told they needed to shift their identity from that of a service program to one of a business.

² Referrals from the criminal justice system increased from 38% of total referrals in 1990 to 59% of referrals in 2004. During this same time period, referrals from welfare and child protection systems increased from 8% to 16%. McLellan, A.T. (2006). Addiction is changing: How changes in systems and customers may affect the Betty Ford Institute. Presentation to Betty Ford Institute Executive Council, February, Rancho Mirage, CA.

"Americans are urged through ubiquitous advertising to construct their identities through consumerism; they are expected to be positive economic actors through consumption."³

The commodification of addiction treatment and its accompanying language has been a corrupting force within the treatment field and set the stage for calls to decommercialize and re-humanize the service relationship. The "consumer" designation is incongruent with the sustained person-professional and peer-peer partnerships being advocated as the ideal models of long-term recovery support. The commercial/commodity aspects of the term "consumer" are also part of a value system that attributes personal value to the possession/consumption of goods and services. It conflicts with a recovery value system that defines personal identity in terms of humility, restitution (paying rather than incurring debt), service (an emphasis on giving rather than owning), and simplicity.

Final Reflection

The addictions field could learn much from the larger disabilities movement of recent decades. Some of the central ideas of this movement include the following:

- Language matters. It is far more than superficial concerns about political correctness.
- Language is imbedded with values and judgments of a culture; cultural change involves a transformation in language.
- The labels applied to individuals affect how they are perceived by others and how they perceive themselves.
- Language is a vehicle of social control and social isolation. Stigma and discrimination are couched in a language that reinforces stereotypes and elicits fear.
- Recovery and community integration require claiming one's own language.
- Language that focuses on the person is more respectful and less stigmatizing than language that defines a person in terms of an illness.

It will be interesting to see how the language of addiction treatment and recovery evolves in tandem with the dramatic changes that are unfolding within these worlds. I hope we will not be talking much longer about "consumers" or "consumer councils" but will instead be talking about people in recovery and recovery (or citizen) advisory councils. I also hope that the paternalistic "our patients," "our clients," and "those we treat" will evolve in the near future to "people we serve."

³ Acker, C.J. (1993). Stigma or legitimation? A historical examination of the social potentials of addiction disease models. *Journal of Psychoactive Drugs*, 25(3), 193-205, quotation from page 203.

People First Language puts the person before the disability, and describes what a person has, not who a person is...People First Language was created by individuals who said, "We are not our disabilities." It's not "political correctness," but good manners and respect. —Kathie Snow

Words can elicit fear, contempt, anger, or pity, but they can also elicit understanding, compassion, and respect. Individuals and families in recovery are awakening culturally and politically. As they do, they will forge their own language to collectively convey their "experience, strength, and hope." They will challenge the traditional language that has been used culturally and professionally to depict alcohol and other drug problems and their resolution. Most importantly, they will claim entitlement to select the words used to refer to those who have experienced addiction and recovery.

Acknowledgements: I would like to thank the following individuals for their thoughtful response and suggestions on an early draft of this paper: Ben Bass, Mike Flaherty, Joan King, Roland Lamb, Joe Powell, and Jason Schwartz. Special thanks to Pat Taylor of Faces and Voices of Recovery for her particularly thoughtful review and suggestions.