Why I Am Not a Consumer

By David Romprey

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When I first heard the word "consumer" used in the mental health system, I assumed it carried with it the powers and responsibilities of how the word is used in other commercial venues.

I became a user of public mental health care in 1987, and I knew that the car industry, for example, was very bound to and appreciative of its consumers. Car consumers had by then driven the U.S. market to profound changes in car size, fuel economy, and safety. Domestic car makers had to listen close to what the American public wanted, and meet their needs and desires in order to draw car consumers away from foreign markets and back to their own.

In 1992, when I became married and my wife and I decided to have a child, I learned soon that pregnant couples, as consumers of health care, had options that were created by mostly women who have rightfully shaped the market more to their satisfaction, comfort, convenience, and dignity. It seems now that physicians have to build into their care as much as they can to resemble mid-wifery values and practices just to retain many couples as customers!

At Alternatives 2004 in Denver, Colorado, I began to think about whether or not *"consumer"* is the word that best depicts our current relationship with the mental health care industry. I truly believe we are heading to a time when we can say this word with meaning, and I don't suggest we give up its use. However, I feel we should look at what are some **key characteristics of a "consumer" in any market**, strive to build these, and by so doing influence and drive mental health services to meet our needs and desires.

First, is it fair to refer to those striving to help us as an *industry*? I insist that it is. The U.S. spends spends nearly $71 billion a year on treating mental illness.[1] Persons needing treatment are suffering humanity deserving of all that stems from the Hippocratic oath, but they are also potential customers that carry profit and gain; and the *helper harvest* for drug companies, hospitals, jails, prisons, managed care organizations, community mental health clinics, and school counseling programs (and the related professional occupations of all above) continues to make happy the reaper. The business is without end in sight. The National Institute of Mental Health, 2002, notes that each year about one in five Americans experiences a "diagnosable psychiatric disability", which includes major depressive disorders, schizophrenia, eating disorders, and anxiety disorders.

Does the term consumer mean that we merely consume the services and medications? **In other words, does sliding the pile of pills off my counter twice each day make me a consumer?** I suggest it makes me a good *consumptive*[2], but not a consumer!

So what makes a good consumer? If standards of consumerism are applied to us as users and customers in the mental health system, what would characterize us as mental health consumers? Although this list could be much improved on and worded in various ways, at minimum I think we would want to show that, as real consumers in our own market:

1) **We have the data.**

2) **We can, do, and will continue to shop elsewhere.**
3) **We attract a following.**

In no uncertain terms is the consumer/survivor/ex-patient (csx) movement substantially close to the above criteria. We are, however, making tremendous headway in getting there, and Alternatives 2004 proved that barriers to these fundamentals of consumerism can and should be removed.

We Almost *But Don't* Have the Data

With mental health programs around the country needing to shape themselves to the strictures of evidence-based practice, the fact that the recovery and self-help movement has long had a laissez-faire attitude about data collection is even more haunting.

Studies of the effectiveness of peer support (see Dr. Jean Campbell's "Peer Support as an Emerging Best Practice, 2003) as well as prolonged analysis of the country's drop-in and self-help group contributions[3] have been a god-send to the csx movement; but linking our own daily achievements to some kind of measurement that the buyers of this industry would care about has so far been a few and far between phenomenon.

However, showing that our specialized efforts actually work (reduce symptoms, keep people out of the hospitals and jails, improve quality of life, improve community integration) should be crucial to us if we want to as consumers get the attention of a market that assumes, like fattened and assuming car makers of the 1970's, to know what we want and need.

Alternatives 2004 did a superb job of focusing on how we can get beyond this major handicap in our efforts by showcasing the workshop *"Getting Peer-Run Programs Ready for Evidence-Based practices*" (Jean Campbell, Ph.D., Steve Leff, Ph.D., Theodora Campbell-Orde). This was a packed-room event where self-help groups from around the nation had the chance to make connections with the Missouri Institute for Mental Health to create plans for ongoing technical assistance to bring their own projects on board the evidence-base statistical silo.

Other Alternatives workshops also pointed to the "empirical impotence" of the csx movement:

- *Consumer-Directed Research to Achieve a Consumer-Directed Mental Health* System (Jonathan Delman and Howard Trachtman, Consumer Quality Initiatives)
- *Introducing ROSI: Consumer-Derived, Recovery-Oriented System Indicators* (Peter Ashenden)
- *Measuring Outcomes Related to Recovery* (Ed Knight, Ph.D., Anita Miller, Psy.D.)

One of these workshops above actually began its blurb in the program with: "Recovery-oriented may need to provide data to support their outcomes." *May?*

Consumers who hope to drive their market must, not may, be able to prove that recovery values and practices in mental health treatment actually work. **Another way of saying this is that consumers, by definition, make their arguments by showing numbers, demographics, statistics, and trends.** The hard business reality is that other ways of approaching their concerns make them *complainants*, not consumers.

The Other Industries Must Be *Insanely* Jealous**!**

Since we actually, as mental health consumers, do not take our business elsewhere, it must drive other industries mad (sic) with covetousness. **We are the easiest and least threatening of all consumers from health care to home improvement, it could be argued.**

Some of our very symptoms (depression, apathy, dependency, fear, passivity) are exactly what you would want if you needed to sell something over and over again without fear of scandal, customer revolt, grievances, and bad press. Thousands die each year in group homes, hospitals, boarding houses, apartments who have lived much diminished lives for most of their lives as essentially career mental patients. These dear souls have given untold profit to the psychiatric care industry, swallowing millions of pills on advice (or command), being billed for hour upon hour of officious social work and interdisciplinary treatment team meetings. In cynical moments, these brothers and sisters seemed to have lived to only be "cash cows" for psychiatry.

What if we discovered ways to access alternatives to traditional mental health treatment in large numbers, and not just frequent the *word "*alternatives"? How have past responses to inferior medical practices and conditions been successful? **Was there ever a shift in so-called modern medicine that didn't fundamentally have to do with either a perceived loss of regular and expected money or the distinct possibility of new money to be had?**

Alternatives 2004, like so many Alternatives in the past, demonstrated the latest achievements of peer-run supports. *Model Consumer-Directed, Recovery-Focused Peer Specialist Initiatives in Broward County, Florida* (William Schneider, MSW and Jana Spalding, M.D.) was a workshop that clearly demonstrated what an "alternative" can do in the lives of persons seeking recovery from mental illness while keeping their places (and getting new ones!) in the community.

Schneider and Spalding, both highly-trained and experienced professionals, shared how they also come from backgrounds of diagnosis and forecasted hopelessness.

How close is Broward County, Florida from establishing their own treatment center? Aside from a physician prescribing medications (and here let me emphasize that Spalding is a manic-depressive M.D. and could dispense "meds" – oops, did I say something wrong, or isn't mental illness on par with diabetes and there should be no stigma and any job for manics under the sun and all that?), what possibly could a "brief/solution-therapy" case manager with 63 clients do that a group of well-resourced peers couldn't do?

Options like this must be created. Medicaid gurus on our side have to be recruited to explain the esoteric pathway that mental health programs acquire when they need Medicaid funding. Many will say, "It can't be done. Medicaid only pays for…" (and you have heard the list). **I say, "There's waivers in them there hills" and if our government thought they could spend less money on a group that is already easily marginalized, they would.**

When we are able to churn out alternative recovery centers and draw billing dollars away from managed care organizations, community mental health programs, and state systems, we will be the buyers, as it were, of Japanese automobiles in the 1980's. And the executives will then, be assured, go to the back rooms and redraw the plan. *Because that, my friends, is the American way.*

"Excuse Me, the Press Suite Needs More Club Soda"

I admit I heard a lot of interesting remarks at Alternatives 2004, but this wasn't one of them, unfortunately. How nice it would have been if the media was there, capturing keynote speaking, following live workshops, and interviewing conference attendees.

Try and name a civil rights movement of the pass that didn't walk hand in hand with the press. The exploits of Frederick Douglas, slave abolitionist, were handsomely covered in newspapers north to south, east to west. We know who marched with the Freedom Fighters up the rural highways to our nation's capitol, because we have viewed the footage! Cesar Chavez's every step, at a certain point, was trailed by the print dogs.

Where are *our* darling journalists? Susan Rogers, in the Alternatives 2004 workshop *Communicating Your Message Through the Media* very capably challenged and trained conference goers on the importance of teaching the populace about our cause.

But we want and need to do much more than offer information! **We must anger and quicken the American public to come to our aid.** The public *should* be angry. The staggering cost of mental health care to the pitiable outcomes is a national waste of resources and lives. The violation of civil liberties and segregation of persons with mental illness is indeed a "bleeding heart rallying cry" as worthy as any other the left has prodded mainstream America to care about in times past and present.

When the periodical *Mother Jones* starts to pick up stories about the csx movement in solidarity, observing if they do true consumerism from our ranks beginning to shape the mental health treatment culture at large, I will leap for joy with exceedingly greater abandonment than when finding out I have won yet another national conference scholarship.

If the *New York Times* on any given day reports that there is a significant trend of public mental health patients who have signed away their treatment authority to peer support networks, brokerages, and holistic private clinics, I might call Joe Rogers and arrange to send him a box of chocolates. "They seem to want employment, higher education, and meaningful relationships.." (I can see the article now!).

Dan Fisher, National Empowerment Center, and featured presenter at Alternatives' luncheon and plenary session *The President's New Freedom Commission on Mental Health and the Opportunities it Offers,* should aspire to be at least as recognizable to the national press as **Danny Glover**. Consider how powerful it would be to have csx leaders who have merged their personalities far enough to carry these issues into mainstream consciousness.

Do we need a Christopher Reeves to stop being Superman to have a voice? Would it help if Kate Winslow started hearing voices, was ran out of Hollywood, given psychotropics and a few isolation rooms, and surfaced seven years later 60 pounds overweight, drawing Social Security and wanting to join her local mental health advisory committee?

Yes! But somehow, we need a following. The public needs to be attracted to our agenda. We have to strategize to do whatever it takes. Who will speak for persons thought to be crazy, dangerous, and lazy? What kind of ingredients and characters do we need to create the mastery of the mediums? It is only this "righteous manipulation" of all forms of media that has a mouse click of a chance in moving an inured and entertainment-toothed society to empathy and action.

Recommendations

1) Encourage SAMSHA to only fund peer-operated programs that collect outcome data.

2) Develop capacity at all national technical assistance centers to train groups on data collection and standards for evidence based practice.

3) Key csx movement leaders lobby with Medicaid for development of waivers for consumer groups who want to offer alternative mental health treatment.

4) At least two regional campaigns to draw substantial number of public mental health users away from localities that have inferior public treatment into viable, competing recovery/treatment options before the year 2008.

5) Grant-writing for a "csx movement media relations office" that is managed by any or all of the national technical assistance centers.

We are not consumers yet. When we have the proof, the purchasing power, the pen and ink of the papers, and attentiveness of the prime time anchors, we will have then lived the definition of the word consumer. We can, must, and will go from consumptives to consumers. *Only our country's remarkable history of not being satisfied with the short, sometimes deadly, end of the stick is on our side.*

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[1] Coffey, R.M.; Mark, T., King, E., Harwood, H.; McKusick, D.; Genuiardi, J. et al. (2000). *National Estimates of Expenditures for Mental Health and Substance Abuse Treatment, 1997* (Rep. No. SAMHSA Publication SMA-00-3499). Rockville, MD: Substance Abuse and Mental Health Services Administration.

[2] *The Merriam-Webster Dictionary* 1997 (*n* : a person who has consumption, from *consumption*, the act of consuming or using up – or – the use of economic goods)

[3] *Consumer-operated self-help programs: A technical report* Tosh, L. and del Vecchio, P. Center for Mental Health Services, 2000)