The Consumer Movement: *History, Rights and Culture*
A Journey from "I" to "Us"

Patients' Rights Advocacy Training

Friday, April 13, 2018

Holiday Inn Sacramento Downtown Arena/Capitol Plaza

Presented by **Richard Krzyzanowski**

Director: California Assn. of Mental Health Peer Run Organizations;

Disability Rights California;

California Assn. of Mental Health Patients' Rights Advocates

Slide 2

What's in a name?

Stigma and labels: A delicate dance
Here are only a few of the names used for, and by, _people with a lived experience_ of mental health issues or a diagnoses:

- Patient / ex-patient
- Client
- Consumer
- Survivor
- Peer

Slide 3

Why a "Client Culture?"

The cultural paradigm allows us to:

- Acknowledge and examine the shared, collective side of the "client experience"

- Provides a framework for educating others beyond our community about who we are, as well as for advocacy and political action on behalf of group interests

Slide 4

Definitions of Culture

- "Culture" refers to the shared attributes of a group of people.
- Collective response to collective experiences
- "Actually, the most important part of culture…is that which is hidden and internal, but which guides behavior." (Hall 1976)

Slide 5

Factors shaping the culture

Important stimuli shaping this cultural experience include:
- Stigma / discrimination
- Poverty / other economic impacts
- Diagnosis / labeling
- Medication usage / side effects
- Forced treatment
- Hospitalization / other institutionalization
- Housing issues
- Unemployment

Slide 6

Client cultural responses

Collective and individual responses have been varied and can often be contradictory. Some of these include:
- The Recovery Philosophy and its values
- The Consumer Movement
- California Memorial Project
- Joining the ranks of mental health professionals / founding peer-run entities
- Self-stigma
- "Learned helplessness"
- Suspicion / mistrust of mental health systems and professionals

Slide 7

The power of history

People labeled as having mental health challenges have been singled out as being "different" enough to merit discriminatory treatment by others in their own societies. Becoming the "other," we have been subjected to a variety of "treatments," including isolation and "warehousing," exploitation for labor or entertainment, abuse and neglect, medical experimentation and sterilization, loss of legal protections and more

Although many of these abuses are behind us in our society, a collective memory of this oppression still exerts a powerful influence on contemporary Client Culture

Slide 8

A portrait

Image of 4 rows and 6 columns of rusted old cans.

Slide 9

Recovery

"Recovery is the process in which people are able to live, work, learn, and participate fully in their communities."

"For some, this is the ability to live a fulfilling and productive life despite a disability."

"For others, recovery implies the reduction or complete remission of symptoms."

— President's New Freedom Commission on Mental Health, 2003

Slide 10

The Recovery Philosophy and its Values

Hope   Empowerment

Self-determination   Freedom of Choice

Knowledge of Rights   Self-Confidence

Self-Advocacy   Responsibility

Developing Peer & Other Support Systems   Resiliency

Slide 11

Recovery perspective

- Recovery can be achieved via tapping into inner strength, resilience, spirituality, self-help strategies (self-responsibility and self-determination), family/peer/community supports, and a sense of connection with other people and society

- People with mental health issues can and often do recover with the support of their peers, family, friends and communities, and by working with mental health professionals for proper diagnosis, treatment and medication.

- People with mental health issues can and do make important contributions to our family and community systems, as well as to the mental health professions

Slide 12

Beginnings: Clifford Beers

- One pioneer of our movement was Clifford Beers. He was one of five children, all of whom would experience psychological distress and would die in mental institutions, including Beers himself. Regardless, he graduated from Yale in 1897.

- In 1900, he was confined to a private mental institution, and would later be confined to a state institution, where he experienced and witnessed serious abuse by the staff. In 1908, he published his best-selling *A Mind That Found Itself*, a groundbreaking account of his experiences. It is still in print.

- Beers then worked to reform mental health systems in America and, in 1909, founded the "National Committee for Mental Hygiene,' now Mental Health America. He also started the Clifford Beers Clinic in New Haven, in 1913, the first outpatient mental health clinic in the United States. He continued in this work until he retired in 1939.

Slide 13

The Consumer Movement

- In the 1970s, a participatory, broad-based consumer movement was born, adopting the guiding principle of, ***"Nothing About Us, Without Us!"***

- Inspired by -- and learning from -- other movements dedicated to claiming and expanding equality of rights and dignity for various constituencies, the Client/Consumer/Survivor Movement mirrored the style and tactics of the Independent Living and Civil Rights movements

Slide 14

Growth and change

- From the early days of standing outside the halls of power with placards, to sitting at the decision-making table today, this movement has been responsible for major changes in its 40 years of organizing. Client representation has made a difference and effected change

- As it successfully made changes, it too needed to grow, master new skills and create new strategies

Slide 15

Movement impacts

Consumers as an advocacy group have effected major system change. There is evidence of system change as a result of consumer involvement at all levels of the mental health system

Client advocates in California were at the heart of discussions that eventually led to the creation of **Proposition 63,** which was approved by voters in November 2004 and became law, officially enacted as the **Mental Health Services Act (MHSA),** effective as of January 1, 2005

Slide 16

It's the law …

Consumer values are embedded in the Mental Health Services Act (MHSA), including:
- Voluntary
- Promotion of self-help/peer support programs
- Involvement of consumers at all levels of mental health systems
- Services that deal with the whole human being
- Involvement of consumers as part of and in training of mental health work force
- Promotion of recovery as a goal

Slide 17

We get results

During public hearings of the Joint Committee on Mental Health Reform in 2000, the Committee Chair knew nothing about the consumer movement or its values.

- We were always at the public mike at the end of the hearing. Client after client shared his/her personal story and/or position on the issues discussed.

- The chair attributes this client testimony to opening his eyes to the client perspective and has been a friend to the consumer movement ever since, even having introduced legislation to restore state hospital cemeteries and limit seclusion and restraints.

- He continues to focus on mental health and disability rights issues to this day.

Slide 18

Voices that made a difference

- Individual consumers have influenced public policy by sitting on key boards & commissions:

- ***Alice Washington*** and ***Vernon Montoya*** sat on the Executive Committee of the California Mental Health Planning Council. The mental health community was debating a new mental health initiative, which became Proposition 63 and then the Mnetal Health Services Act (MHSA).

- At an Executive Committee meeting, Alice and Vernon said that the Initiative wasn't consumer friendly enough. They were invited to write language that would be more client friendly.

Slide 19

The results

What Alice and Vernon created became a part of the MHSA, and can be found in state law: WIC Section 7, 5813.5 (d)

- (d) Planning for services shall be consistent with the philosophy, principles and practices of the Recovery Vision for mental health consumers.

- (1) To promote concepts key to the recovery for individuals who have mental illness: hope, personal empowerment, respect, social connections, self-responsibility, and self-determination.

- (2) To promote consumer-operated services as a way to support recovery.

- (3) To reflect the cultural, ethnic, and racial diversity of mental health consumers.

- (4) To plan for each consumer's individual needs.

Slide 20

Creating a legacy

Vernon Montoya made yet another major contribution to the mental health landscape of California:

- During conversations about the importance of cultural competency in a our diverse state, he proposed the need to recognize that there is a Client Culture that deserved recognition as well

- Vernon helped to develop the concept of Client Culture, which is now mandated as part of ongoing cultural competency training in every County.

Slide 21

More evidence: National impacts

Recovery replaces maintenance as the goal for people diagnosed with mental health challenges:

"We envision a future when everyone with a mental illness will recover."

--- From the **President's New Freedom Commission on Mental Health**, "Achievibng the Promise: Transforming Mental health care in America," Final report, July 2003

Consumers have initiated new genres of services: Consumer-run programs and peer support are now designated as evidenced based practices and are essential components of most mental health systems.

Slide 22

California Memorial Project

People with developmental and mental disabilities share a common history at state institutions.

Since the first institution opened in 1853, people were committed to state institutions for a variety of reasons that would be unacceptable today. Up until the 1950's approximately 10% of the hospital population died each year.

For a variety of reasons, people were abandoned by their families. As a result people were buried at the hospital grounds in unmarked cemeteries.

Slide 23

California Memorial Project

Over time these cemeteries had mostly fallen into disrepair, were neglected, or were sold and/or used for other purposes.

Also, when state institutions closed, people were exhumed and moved to county cemeteries in unmarked graves. Many times people were placed in unmarked community graves. Part of the project involves locating were people were moved.

Slide 24

California Memorial Project

The Project works to restore and properly memorialize the cemeteries still on state hospital and developmental center lands, and those grave sites of people in county cemeteries, who died in institutions.

People who have lived in state institutions are leading the way to bring honor and dignity to those who have died in a state hospital. It is their voices and experiences that guide this project.

The Project also works to record the stories of people who lived in the state institutions by decade, and document the history of the consumer/survivor movement in California.

Slide 25

The challenges of change

We have looked at several collective and individual aspects of client culture, some positive and some negative.

Culture can change slowly, sometimes not keeping up with change in the environment. Attitudes and behaviors can persist long after the reasons for their existence have gone, and individuals can perpetuate responses to cultural stimuli that they did not even directly experience.

One such example involves a general, lingering suspicion/mistrust of MH systems, culture and professionals

Slide 26

From "client" to colleague

- Along with housing, employment has consistently ranked as one of the highest priorities for clients of the mental health system (as well as for people with other disabilities)

- The inclusion of people with a lived experience of mental health issues into the mental health professions is transforming both client culture *and* mental health systems/professional culture

Slide 15

The Road Ahead

- Peer Support Specialists
- A commitment to "Systems Transformation"
- Peer-run organizations
- Internal diversity tactically; advocacy
- Internal diversity: age, class, color & self-definition
- Embracing external diversities and alliances