

How Consumers Came To Be Part of the MHSIP Community

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How Consumers Became Part of the MHSIP Community: Part 1

For many years people had gathered in small and large groups at conferences, state halls and the various hallways of hotels and restaurants to debate the mysteries of mental health data. If you listen hard, you can still hear the voices from a decade ago cry out in search of “comparable data” and “decision-support” to improve the lives of people with mental illness.

But distant drums of change were heard in the void—a stirring of the idea to include consumers, themselves!

“Comparable data”

“Decision support”

“Consumer involvement”

Part 1: Setting the Stage

- In the early 90's when the MHSIP Ad Hoc Advisory Group first considered bringing a consumer or family member into their group, there existed only two primary consumer Technical Assistance Centers. Unlike the family movement, there were many small consumer organizations but no national organization, nor were there any groups with a focus on research or policy.



*“So let’s invite a member of the National Alliance for the Mentally Ill.”
That will be good.*

Statman rises up—“No, why not get someone who is receiving mental health services?”

“You mean someone that actually has severe and persistent mental illness?”

“But where will we find such a person?”

“Where should we go?”

“What organization should we contact?”

Part 1: Setting the Stage

- On the local and state levels consumers were beginning to be involved in policy and evaluation.
 - State Planning Councils include consumers
 - Consumer representatives join MH Boards
 - Ann Loder presents plenary “Hope with a Capital H” at National Mental Health Statistics Conference (1991)
 - Jeanne Dumont becomes first consumer member of MHSIP Ad Hoc Advisory Group (1992)

At the same time on the outskirts of the MHSIP community, consumers also began to see the power of data.

“Nothing about us, without us!”



The stage was set for multi-stakeholder partnerships within the MHSIP community.



Part 2

A primary consumer was added to the MHSIP Ad Hoc Advisory Group and some were invited to join the regional RUGs.

Almost immediately these new consumer members started calling forth—

“We’ve got to get more people!” “The few of us cannot represent the entire consumer movement.”



And so, the Consumer/Survivor Mental Health Research and Policy Work Group was born. And the gods of CMHS smiled, and opened their wallets.

Part 2: Sharing a New Perspective

- Offices of Consumer Affairs are established in SMHAs across the nation.
- The Consumer/Survivor Mental Health Research and Policy Work Group is formed to provide national consumer input into mental health services evaluation and policy decisions.
 - First meeting of the Work Group is held at the Mayflower Hotel (1991) with over 25 consumers experienced in research and policy issues present to discuss the need for consumer values in mental health outcomes.

But consumers wanted more than a seat at the table. They wanted to advance their perspective. They wanted meaningful inclusion in producing mental health statistics.

Confusion raged within the MHSIP community.



The wise MHSIP elders called out—

“Why don’t you tell us what you want and we will do the research?”

“But some of us are researchers!” the consumers proclaimed.

And they began to chant—

“Comparable data.”

“Decision-support”



And the MHSIP community joined in a multi-stakeholder chorus.



“Comparable data.”

“Decision-support.”

But the Consumer/Survivor Work Group was still troubled.

Part 2: Sharing a New Perspective

- MHSIP 2000 (1995): Jeanne Dumont and Ann Loder marshal a critique of the FN 10 and the future directions of MHSIP.
- Humanizing Decision-Support (1993): Jean Campbell creates a collaborative vision for decision-support through person-centered communication technologies.
- Mapping Outcomes from the Perspective of Consumers/Survivors (1993, 1994): Jeanne Dumont leads the Work Group in two ground-breaking concept-mapping sessions to define SMHA outcomes.

“This new idea of looking at outcomes does not include the consumer values”

“Personhood”

“Empowerment”

“Recovery”

“Freedom”

“The negative outcomes of forced treatment and medications must be looked at.”



“Fear”

“Hopelessness”

“Learned dependency”

“Dissatisfaction”



With help from MHSIP, consumers met. Focus groups conducted. Papers written. Consumers started fanning out to conferences all over the land.

From the audience were heard impassioned pleas—

“We want to be on these panels.”

“We want to share our insight.”



***Distractors resisted,
“Consumers lack insight!”***

Consumers responded—

*“We are here to stay
We are at the table
We are not going away
Nothing about us, without us.”*



Allies came to the forefront to proclaim, *“Consumerism is not a fad!”*

Part 2: Sharing a New Perspective

- The Technical Assistance Needs of Consumer/Survivor and Family Stakeholder Groups within SMHAs (1998): Jean Campbell prepares a report assessing the Consumer Component and Family Questions of the NASMHPD SMHA Profiling System.
- The MHSIP Mental Health Consumer-Oriented Report Card (1994-present): Consumers and mental health professionals collaborate to produce an outcome tool grounded in consumer values to evaluate mental health service systems.

Not always have consumer insights and collaboration been welcomed or understood. Often, more bridging and work has been needed to build acceptance of difference and perspective.

For example—The MHSIP consumer report card was celebrated as “by and for consumers” because it was borne up from the values of consumers, and the desire to hold mental health systems accountable through outcomes data and performance measures. But there was a bit of a “Mess-up” at MHSIP.



“Comparable data.” “Decision-support.”

Shouted the data professionals.

“There are no validated measures for such things as personhood, recovery, dissatisfaction, coercion.”

And so there was discontent in the land until a consumer suggested--

“Let’s call it a consumer-oriented report card.”



And the great compromise was forged. Consumers rallied to the vision of a report card that would access traditional mental health programs and make them accountable for quality, outcomes, appropriateness, and the satisfaction of service recipients. Some consumers became surveyors, others developed

assessment teams. Some have fought on to validate and include indicators of personhood, recovery, dissatisfaction and coercion.



Part 3

As we stand here today, we can look back at the many changes to the mental health system that have occurred. MHSIP has been a leader in reforming how services are monitored and consumers are involved in the decision-making process.

**Part 3:
A Clearing Horizon**

- **Mental Health, United States, 1998:** Jean Campbell reviews the literature on consumerism, outcomes and satisfaction.
- **Mental Health: A Report of the Surgeon General (1999):** Led by Ruth Ralph, a group of consumers contribute to this seminal mental health report.
- **Review of Recovery Literature (2000):** A synthesis of recovery literature is prepared by Ruth Ralph.
- **Facilitation of Recovery (2000-present):** A consumer work group conducts a grounded research effort through state focus groups to develop an instrument to measure how SMHAs facilitate recovery.

The challenge is to continue the progress that has been made—

Respect one another's opinion.

Meet as equals.

Value the struggle.

And, when possible, help each other avoid the “potholes” along the Information Highway.

Or, at least grab a partner, and as Ann Loder (one of the founding members of the Research and Policy Work Group) often did, get up on the floor and boogie.

“Comparable data.”

“Decision-support”



with a little rock-n-roll.

