



New York State Consumer White Paper

Infusing Consumer Driven
Rules/Values into the Mental
Health System

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Institute of Medicine

Crossing The Quality Chasm: A New Health System for the 21st Century

1. Care Based on continuous healing relationships
2. Customization based on patient needs and values
3. The patient as a source of control
4. Shared knowledge & free flowing information
5. Evidenced Based decision making

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6. Safety as a system of property
7. The need for transparency
8. Anticipation of needs
9. Continuous decrease in waste
10. Cooperation among clinicians



New York State Consumer Dialogue Campaign

- Met with over 200 consumers throughout New York State
- Had additional dialogues with over 400 other consumers in NYS
- Presented and obtained feedback from over 3,000 consumers
- Drafted paper

The ten rules developed by the NYS consumer stakeholders

1. There must be informed choice
2. It must be recovery focused
3. It must be person centered
4. Do No Harm
5. There must be free access to records

The ten rules developed by the NYS consumer stakeholders

6. It must be a system based on trust
7. It must have a focus on cultural values
8. It must be knowledge based
9. It must be a partnership between consumer and provider
10. There must be access to services regardless of ability to pay

There Must Be Informed Choice

- MD/Psychiatrist/Therapist are required to inform consumer of short and long term side affects of medication prior to subscribing any medication
- Consumer should be informed of all available forms of treatment and alternatives to clinical treatment, i.e., holistic, peer support groups, etc
- Once informed, decision should be independent or collaboratively



[It Must Be Recovery Focused]

- The community must understand the definition of “Recovery” and support it
- People should be able to move forward at his/her own pace without judgment or labels
- Payment to providers must be based on the recovery of the individual (Outcome Based)
- Ability to move in and out of the system without loss or delay of services
- Allow failure as well as success

[It Must Be Person Centered]

- Treat the person and his/her circumstances, not just the diagnosis
- Respect and Value each person
- Provide information on diagnosis
- Promote choice and recovery
- Develop common goals
- Provide open dialogue about risks

Do No Harm

- Elimination of restraints and seclusion
- Proactive treatment vs. reactive treatment
- Validate a persons reality and circumstances
- Refer to our Advance Directives or Wellness Recovery Action Plan before reacting to a situation

[Do No Harm]

- Build trust through active listening and validation
- Honesty among all parties
- Guarantee a safe environment
- Listing all options and allowing time for the consumer to make the decision for type of treatment offered

[There Must Be Free Access To Records]

- Consumer participation in record keeping
- The right to read what is written
- Immediate access to all records
- Remove mistakes or misdiagnoses from permanent files

It Must Be Based On Trust

- Adherence to confidentiality
- Honesty about prescription medication
- Reciprocal sharing between provider and consumer
- Active listening and responding to every consumers concerns
- Building trust through staff retention
- Trusting consumers to make decisions, right or wrong
- Humanizing consumers as whole people

It Must Have A Focus On Cultural Values

- The community must be educated on cultural norms, customs and role identification
- Bilingual services should be available
- Literature associated with mental health services and cultural norms
- Spirituality, sexual preference and gender differences should be treatment sensitive

[It Must Be Knowledge Based]

- Understanding the illness by understanding the person
- Knowledge of all options towards recovery
- Knowledge of benefits and side effects of medication or “alternative” therapies and practices

[It Must Be Knowledge Based]

- Knowledge of the possibilities of a better quality of life despite diagnosis
- Education of mental illness should start in early education to reduce stigma and discrimination
- Families should be educated “together” about the illness, medications and recovery possibilities

It Must Be Based On A Partnership Between Consumer And Provider

- Consumer choice in selecting a provider
- Both parties agree to strict confidentiality
- Create an environment of comfort, trust and respect

It Must Be Based On A Partnership Between Consumer And Provider

- Agreement of goals by both parties
- Sessions that are open to negotiation
- Elimination of a system based on punishment
- Consumer as the professional in deciding who can be involved in treatment

There Must Be Equal Opportunity To Treatment Regardless Of Benefits

- Treatment dictated by the illness, not payment benefits (Equal Treatment)
- Opportunity for second opinion
- Choice of provider/clinician/program or alternative treatment
- Elimination of “sanctions”

What's Next?

- Get the Stakeholders to review and approve the final copy of the White Paper
- Develop measurement tool for the 10 rules. (Fidelity Measures)
- Deliver the paper to OMH

Then What?

- Consumers and/or Providers/OMH/LGU's Partner to develop a methodology of infusing the rules.