

INFUSING RECOVERY-BASED PRINCIPLES

INTO MENTAL HEALTH SERVICES

A White Paper
by People who are New York State
Consumers, Survivors,
Patients and Ex-Patients

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Consumer/Survivor Involvement in EBP's: Why a mite Paper?

IN THE WINTER of 2002, New York State Office of Mental Health (NYS OMH) began to work in partnership with people who use or have used mental health services to infuse their perspective into their evidence based practices initiative. At that time, a widespread Evidence-Based Practices (EBP's) awareness building campaign got underway. This campaign offered education on the national EBP's trend and focused on NYS's priority set of EBP's, which included self-help and empowerment. The goal of this campaign was not only to educate people on this issue, but to seek out input and guidance that would answer the question, "How can NYS OMH infuse recovery-based principles into Evidence-Based Practices?" As the campaign moved forward, over 6,000 people participated in consensus-building dialogues that would create and refine this white paper. In addition to these dialogues, an EBP's and recovery consumer/survivor steering committee was convened and the involvement of people who are current and former users of mental health services was infused into many of NYS OMH's internal workgroups.

The debate over the value of EBP's within the consumer/survivor community was well known to the EBP's consumer/survivor steering committee. It was decided that rather than focusing on this issue, we would use NYS OMH's focus on EBP's as an opportunity to improve mental health services as a whole. As a first step, this steering committee discussed a document delivered by the Institute of Medicine (IOM) called *Crossing The Quality Chasm: A New Health System for the 21st Century*¹ and agreed that the ten rules that the IOM recommended for a qual-

ity health care system (below) would be a good place to start. The IOM's Crossing the Quality Chasm Report suggested the following rules:

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 flow of information
5. Evidence-based decision making
6. Safety as a system property
7. The need for transparency
8. Anticipation of needs
9. Continuous decrease in waste
10. Cooperation among clinicians

These rules were discussed in two inclusive meetings of people who were current or former users of mental health services and a new set of draft rules was created that would be specific to mental health care in NYS. These new rules then became the focus for eleven dialogues with participation from over two hundred people. The content of these dialogues was then summarized and brought out to approximately 6,000 additional people for their reactions and input. After giving input into the creation of the rules, each participant selected his or her top three

¹ Institute of Medicine: Committee on Quality Health Care in America. *Crossing the Quality Chasm: A new Health System for die 21st Century*. Washington (DC): National Academies Press; 2001

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rules, and the results were then tabulated in a ranking order to determine importance. Those of us involved in the dialogues want it stated that all of the rules are equally important; however, there is a level of hierarchical importance that must be considered. Below is a list of our rules in prioritized order.

The Ten Rules for Quality Mental Health Sen/sees in New York State

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 FreeAccessTo Records
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 Based On A Partnership Between Consumer & Provider
10. There Must Be Access To Services Regardless Of Ability To Pay

Introduction

New York State Office of Mental Health's (NYS OMH) Evidence-Based Practices (EBP's) models have created an interest and call to action to infuse input, our input, into creating and measuring quality mental health services throughout New York State. This is our opportunity to create a vision of recovery that we have been working so hard to achieve through fragmented actions all over the state. This document takes all of these fragmented ideas from people who are consumers, survivors, patients and

ex-patients who live in every region of New York and puts a dear picture together as to what quality, recovery-based services would look like. We acknowledge that many recovery processes are independent of and beyond the boundaries and responsibilities of mental health services. In an attempt to achieve our goal, we will be focusing only on how New York State can create services that can support an individual on his or her recovery path.

It should be noted that although many of us support evidence-based practices, this white paper is not a result of consumer/survivors promoting this initiative. Instead, it is a movement toward infusing our definition of quality into evidenced-based practices or any other initiative within the mental health service delivery system. Our definition of quality is derived from our collective experiences and who we are as individuals. This white paper is the first step to bring attention and gain support to infuse clear and measurable indicators of quality into all aspects of the mental health system that will guide individuals toward self-help, empowerment and self determination. The idea being that no matter what kind of mental health services are delivered, if the new rules were applied, the recovery outcomes for people who use mental health services would increase. This is our attempt to bring the mental health system to a more level playing field for professionals and people who use mental health services. It is a person-centered approach that we believe is long overdue in the mental health community.

If we are to truly change the culture of mental health services in NYS, the rules outlined in this white paper must be infused into OMH's evidence-based practices initiative as well as any and all mental health initiatives delivered through local governments and provider agencies. These rules are, in essence, a call to arms for providers and consumer/survivors to break down the barriers that have existed for so long between us and build relationships that promote individuals as whole persons and looks beyond illness towards a new world of hope and wellness. If these rules are implement-

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ed, we believe they will bring each one of us closer to the goals of independence, self-determination and personhood, which are basic human elements utilized by all "successful" individuals in society. It brings the stigmatized, powerless, discriminated individual into parity with the community.

The relationship that exists between a person who uses mental health services and a service provider is at the heart of the rules set forth in this document. As you read further into this document, you will begin to recognize an underlying theme that emphasizes the power of listening. It will be made apparent that those of us with a mental health diagnosis gain invaluable hope and self-determination through knowing that we are being listened to and that our thoughts and feelings are being validated and respected. It is the essence of listening that begins the process of recovery and then it is built upon through trust, relationships and interdependence between the individual, the professional and the community.

Since we believe that it is up to each individual to either solely, or in partnership with trusted others, decide how to participate in recovery, this white paper is not examining "what" recovery is. Rather, we chose to focus on "how" to help one find and walk his or her personal recovery path. It must be recognized that there is a process to recovery and that it is extremely individualized for every person. There are guiding principles, philosophies and beliefs based on scientific and anecdotal evidence that promote recovery, but there is no cookie cutter model that will do it all. It is our hope that this paper will help one understand how to support someone on their path to recovery by laying out some simple rules that have been recommended by those of us who have first hand experience with the mental health system.

RULE # 1

There must be Informed Choice

Our collective definition of informed choice is best stated as obtaining useful information from the

practitioner or professional and then deciding individually or collaboratively on the best course of action that promotes independence, recovery and an improved quality of life. This means that the professional must be knowledgeable and exhibit flexibility and openness toward information related to recovery, which may include treatment programs or treatment options that are holistic or services that are complementary to traditional treatment. This would include benefits and possible pitfalls to any treatment. Informed choice includes an educational approach to medications and side effects on behalf of all parties so that sound knowledgeable risk can be decided upon by us or collaboratively with the family, friends and/or our practitioners.

This issue of medication is extremely important to those of us involved in the dialogues as the current status of medication administration is mostly seen as coercive and forceful and offers little or no information on what medications are doing to us beyond the treatment of symptoms. Medication education for prescribers, practitioners, therapists and peers is of the utmost importance and must be a priority. Informed choice cannot be exercised without accurate information. Many of us are quite capable of making decisions even if we are experiencing a severe emotional state of mind or presence. A system that promotes recovery would have genuine informed choice as the foundation of its service delivery.

We also feel that informed choice must be a part of goal setting. One participant felt that, "Information should be up front before any decisions are made." Additionally, service planning that is built upon a foundation of informed choice should take into account the whole person, not just the mental health-related symptoms. For example, spirituality, cultural background, physical well-being, community connections and social supports are essential considerations.

On a final note, a system that truly values informed choice will assure that each person who walks through the doors of the program is offered education on Advance Directives. Additionally, if

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someone within the program or service has an Advance Directive, the contents of that document would be respected and valued as a legitimate statement of the person's treatment decisions.

RULE # 2 **It must be Recovery Focused**

Recovery is individualized and personal and is not a product for the world to witness and judge. We believe that a recovery-oriented system would allow people to move forward at their own pace, without judgment or labels and would present opportunities for wellness and life development that are built upon a foundational belief that healing is possible and very real. Many of us feel that a recovery-oriented system would allow for failures as well as successes. In the past, many of us have experienced loss of support when we needed it most because we have not been able to move in and out of the system with ease.

Services that are recovery focused look beyond the traditional medical model to other fields, practices, cultures and perspectives. A recovery-focused process involves a strengths-based approach that promotes a mutual connection between the service provider and the person who is using mental health services that instills trust and hope. When a professional looks beyond symptoms and gets to know us as whole people, the foundation for recovery is being set. It cannot be stressed enough that listening and validating our humanity is key to developing a healthy trusting relationship. Without a positive healing relationship and trust, a roadblock to recovery is created. We become victims to static, hopeless "programs" and exhibit little or no growth. We lose our self-esteem and hope is shattered.

One of the barriers to having a recovery-focused system is lack of education. There must be an education process developed in collaboration with providers and the person who is using the service for the community at large that addresses discrimination by proving that people can and do recover

from mental health issues. Additionally, we feel that knowledge is power. For that reason, educational materials need to be available at all service delivery points and must include, but not be limited to the following topics:

- Coping Skills, Self-Advocacy Skills
- Socialization and Recreational Opportunities
- Local Peer-Operated Programs & Advocacy Services
- Educational Opportunities & Entitlement Information
- Alternative Treatment Self-Advocacy
- Self-Help & Empowerment Services & Peer Support Groups
- Crisis Diversion Programs
- Vocational Opportunities
- What are Recovery-Oriented Services?

When we use mental health services, we are "customers" of that service. To us, that means that once we create a goal, it should be measurable, and funding should be tied to the successes or failures of that goal. The funds should be under some sort of control of the person to empower him/her in deciding whether the services that he/she is getting are quality, recovery-oriented services and that the provider is worthy of continued receipt of funding.

RULE # 3 **It must be Person Centered**

We believe that for mental health to be person centered it must be delivered in a manner that is respectful, valued, validating and consistent. Person-centered planning requires a partnership that is a collaboration of ideas that solely focus on

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us as individuals and helps professionals understand that the consumer is the "hub of the wheel."

Person centered planning must be driven by the person's strengths, values, culture, beliefs, spirituality and preferences. By recognizing personal values and by consistently treating the consumer with respect and dignity, treatment plans are truly individualized as they identify with the whole person. In addition to being strengths focused, it is most important to note that the person who is using services is in charge of the planning. In the past, many of us have felt as if we were having services done "to us." For true person-centered planning to occur, we must be central to the decision making. We also feel that it is very important that we have the option to involve our support system in our planning. This support system should not be limited to traditional definitions of family and/or significant others, but should be expanded to include friends and peers.

Person-centered care focuses all outcomes on the individual's life in regards to housing, benefits, jobs, health, family, recreational choices, relationships and any other aspects of life that human beings may experience. Person-centered planning must not be economically driven but rather treatment driven based on our terms, our choices and our individualized needs. Most importantly, person-centered planning must not be time restricted.

In the past, some of us have experienced service providers who have instilled guilt when a choice is made or when we don't find a suggestion favorable to us. This type of coercion has been a common barrier that has prevented person-centered planning.

RULE # 4 Do No Harm

Many of us agree that there have been times when our stays in hospitals and mental health programs have contributed to our problems and even re-trau-

matized us. We would like to see the following procedures included in any service delivery system:

- Refer to our Advance Directives and/or Wellness Recovery Action Plan and follow instructions within these documents before reacting to a situation.
 - Consider "Forced Treatment" as a system failure. "If you have to force me to use your services, you have failed to engage me in the treatment process. This is not my failure, it is yours." This could be addressed by having service providers think outside the box by offering new and innovative services might be used voluntarily.
 - Eliminate restraint and seclusion as it only makes us feel •worthless and inhuman. "We are in a hospital to heal, not to create deeper wounds or further trauma."
 - "The term non-compliant is representative of the perspective that the provider is the expert, and it assumes that I am not an equal partner in my services." Providers should recognize that the use of this term is a covert form of coercion, and it works against a partnership based on respect. For that reason, use of this term should be discontinued.
 - Selectively partner compatible people that we choose as roommates so that our stay in services can be as safe and comfortable as possible.
- ¹ Listen to us and be patient and respectful when we ask for your time and attention.

Discuss a variety of treatment options and allow us the time to make an informed choice.

If we request the involvement of our family, friends or significant others, they must be fully informed of treatment options and risks on a regular basis.

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Additionally, this rule applies to the community at large. For example, we feel that education for law enforcement agencies is a priority so that police officers do not react in an aggressive manner which might create a more dangerous situation. Society as a whole must be educated on mental health issues so that they are aware that we are not dangerous people. Education would be helpful in reducing discrimination as people would learn to treat us with dignity and respect, no matter what emotional state we may be experiencing.

RULE # 5

There must be Free Access to Records

Access to records is an issue that has historically been and continues to be problematic for those of us in the mental health system. Our families also share this frustration. Some of us have experienced long waiting periods for our records and copying fees that we can't afford. For this reason, we would like to see access to records simplified by allowing free, uninhibited access to us from hospitals, psychiatrists, doctors, clinics and therapists. For those of us who make requests for records and are denied, we would request that services be mandated to have Clinical Access Review Committees so a grievance process can be followed.

Our experience also leads us to want more accurate record keeping that is created jointly with the person who is using the service. Additionally, we want to have the ability to change or comment on records without having to go through a lot of "red tape." This particular rule is important as it allows us to not only access our records, but empowers us to participate in a permanent "story" about us.

Providers should also be sensitive to the fact that mental health records are viewed differently than traditional health-related medical records. Mental health records keep us from getting good jobs or certifications in specialized fields. Mental health records can be great barriers to achieving a quality of life that is free from stigma and discrimination.

That is why we must have more input into our records and more adequate training must be offered to providers in this area. We have the right to insure that the truth is written about our lives.

The Health Insurance Portability Accountability Act (HIPAA) leaves us hopeful that this is a major step toward accessing our records and protecting our confidentiality. However, we would like it stated that although we are promised confidentiality within mental health services, it often is not adhered to. This issue should be taken more seriously and offenses should be more aggressively enforced.

RULE # 6

It Must Be Based on Trust

Trust is the key to creating an environment that promotes recovery. Where there is honesty and trust, there is a strong, healthy relationship. Most of us who have participated in this dialogue have stated repeatedly that trust and listening are the most helpful forms of "treatment" that exist in supporting the recovery process. By listening more intently, a professional can begin to more comfortably trust a consumer's perspective and let go of the controlled responses that have been infused into some modes of treatment. We agree that coercion and fear have been barriers to trusting mental health providers, and a relationship based on trust and equality would drastically eliminate this as an issue.

We consistently witness this in many of our self-help groups. Self-help groups foster an environment of hope because we see each other as equal "people" and interact in a healthy, healing, supportive and trusting environment. It is not always that way with the professional community. Many of us have experienced providers who come across very stale, clinical, sterile and boundary restricted. We want to develop relationships that foster an environment of equality and informed choice within the mental health services that we choose to utilize. Specifically, our goal is to have the provider discuss the pros and cons of every

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treatment option in relation to the individual and not focus primarily on our diagnosis. For this relationship to exist there must be mutual respect. We recognize that mental health professionals have expertise. We also ask for recognition from the professional that we have expertise of our own because we live it every day. Additionally, open communication, honesty, clear expectations and active listening are essential tools in the development of a relationship built on trust. Unfortunately, many of us have examples of how this is not occurring. When a trusting relationship is present, a service provider will give accurate information and education on the following service choices:

- Medications Gong/short-term side effects; "What does it do to me?")
- Therapy (What is it? Is it recovery focused?)
- Programs (IPRT's, DBT, etc, and What are the expected outcomes of each program?" "How long will I have to attend?")
- Housing ("What options exist? Will this promote wellness? Does it place me back in the "bad" section of town?")
- Alternatives ("What if I do nothing? What other options exist? What do you know about alternative therapy?")

The trusting relationships must also extend to consumer-run programs, peer support services and self-help groups through honest, direct communication, support and equality. Trusting partnerships between consumer-operated services and providers can be beneficial as they may result in collaborations that educate the community about recovery and address discrimination. It should be recognized by the community that it takes a village to recover, and this should be done by maximizing resources through the collaboration of peer-run and traditional services that are based on a trusting relationship.

One of the barriers to achieving trusting relationships is that we believe that the professional community is constantly "under the gun" to deliver units of service numbers for the funding regulators. The human factor is often left out of this equation. The system of reporting as it currently stands does not show any type of recovery-focused outcomes. Additionally, it inhibits focus on us, as consumer and emphasizes that the reporting guidelines are more about numbers than people. This barrier could be addressed by allowing us to be a part of the reporting through the development of recovery outcomes.

We would like to have The Office of Mental Health and local government entities involved in this trusting relationship as well. We would like to see greater collaboration on new programs and initiatives, and this white paper may be a very good start in building that trusting relationship.

RULE # 7 It Must Have a Focus on Cultural Values

There is a desperate need for services that are effective across all cultures. Many of us report having language differences with service providers that impede our progress and having less access to quality services because of where we live. Once services are accessed, some of us reported feeling discriminated against because of our culture and our beliefs. Below are concrete ways in which culturally competent mental health services should be provided:

- Consider that mental health services are unique based on regional differences throughout New York State. Those of us in New York City may have many service options, where those of us in Saranac Lake may be limited to one. When you speak of choice, please remember that this is our reality.
 - Mental health service providers and the community at large should not be afraid to ask us about our beliefs. Many of us reported using
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mental health services and never being asked about our culture and how that might impact our recovery. Your questions are welcomed because they foster understanding.

- Train providers on how to provide culturally competent services and expose them to the beliefs of other cultures through speakers and presentations.
- Hire staff that is reflective of the community the program serves.
- The professional community must recognize differences in individuals and adjust treatment according to our cultural experiences. Get to know the cultural groups that make up our communities. Don't just assume that you know who we are.
- Providers must "embrace" differences in those of us who are not from similar backgrounds by working to understand language and being understood. It is too often that we cannot understand what our psychiatrist is saying or he/she can't understand us.
- More information needs to be translated into other languages.
- Providers need to offer more culturally-competent peer advocacy for recipients.
- Cultural values unique to the hearing impaired community as well as those relating to the consumer/survivor community should be considered.

Additionally, there is a need to develop an educational program that teaches providers, local and state governments and other recipients in the community about the culture of healing and recovery that is socially sensitive and progressive.

RULE # 8 **It Must Be Knowledge Based**

Providers must have accurate, up-to-date knowledge of clinical practices, treatments, holistic healing methods and complementary methods. This knowledge empowers us as well as the professional in making sound decisions as partners with full understanding of the risks and possible outcomes. All different modes of care should be explored and learned so that we do not have to "settle" for services that have not worked for us in the past. There are some very helpful alternative or holistic ways in which to get well and stay well.

Additionally, it must be understood that knowledge does not just come from books and research, but it comes from all of our stories, our experiences, our failures and our successes. Part of a knowledge-based service approach is gaining knowledge about what we already know about ourselves, our experiences with medications and services, our culture, etc. Maintaining this kind of asking stance promotes greater sensitivity towards all parties, and it promotes respect, which is essential to a supportive healing relationship. Life experience and qualitative research should be considered valuable evidence to support or denounce a particular practice and/or service. Some of us believe that knowledge is built upon the bias and preconceived notion of whoever builds that knowledge base. We are not asking that die only knowledge that be considered be that of peers, but that the knowledge and experiences of peers be considered equally as valuable as book knowledge and scientific research. Additionally, knowledge of what experience proves ineffective is also valuable as it aids in understanding what doesn't work and creates an opportunity for quality improvement.

If shared in partnership with the recipient, we feel that patient rights education and sharing knowledge that is offered in the spirit of genuine informed choice reduces coercion and promotes trust. Some of us reported being informed of our rights and responsibilities as recipients for the first time when

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we were in *a* full-blown crisis. There must be *a*. commitment to wide spread education about our rights, our responsibilities, medications, service options, etc. and it must reach far beyond our admission to a facility. This knowledge also needs to be more widely dispersed and done much sooner.

We would also like to see consistent communication developed between providers and not just "chart updates." Our information should also be kept updated and communicated so that we do not have to constantly repeat our story over and over. Knowledge of our advance directives must also be communicated, respected and implemented.

In the past, many of us have been labeled as "difficult" or "noncompliant" when we spoke up on our own behalf or on behalf of someone else. Our knowledge of self-advocacy must also be respected just as many other people advocate for themselves in other health care or human rights situations. Our ability to speak up on our own behalf is indicative of our growth and should be celebrated by providers as a success. We also need to be able to educate families, professionals and the community about recovery and healing through success stories and even stories of despair that show the resiliency of the human spirit.

RULE # 9 It Must Be Based On A Partnership Between Consumer & Provider

We would like a partnership with the providers where needs and expectations are clear to all parties. This partnership would be marked by equal participation in treatment and open, honest communication. We want a relationship with a service provider that leaves us feeling safe to agree or to disagree on issues without fear of repercussion or punishment. It should be an environment void of coercion and one that encourages the asking of questions by all parties. This reinforces trust between consumer and provider and vice versa. This partnership also includes treatments that are

more individualized and more comprehensive in relation to us as a "whole person.

A professional sharing something about him/herself helps create trust with us as well. Examples of information that can be shared is 'where you went to school', 'why you are a psychiatrist or therapist', etc. When we see the professional reach out to us and open up, we think of the professional less as a drug dispenser and more as a person helping us maintain trust and hope. When this occurs, it shatters the "us versus them" mentality that has existed in the mental health culture by making a statement that we are partners, and we are working together on common goals.

Another important part of developing a partnering relationship is to open up the communications to negotiations. Being flexible and open to new ideas and trusting that our opinions and feelings count and are important. These ideas, opinions and feelings are what keep us well at times, whether the professional agrees or disagrees with them. This idea of developing a partnership suddenly puts us all on the same page. We become collaborators and advocates together and begin a new vision of recovery and healing.

RULE #10 There Must Be Access To Care Regardless Of Benefits/ Lack Of Benefits

This rule, which was first suggested in Buffalo, New York, grew to become a very important issue with most of us in New York. The rule is simple. There must be a total elimination of "sanctioning" of people that are in need of public assistance. This includes social services public assistance, Medicaid, food stamps and temporary housing. These are the services that we need to begin our road to recovery.

It is often difficult for some of us to obtain the proper paperwork that DSS or the Medicaid office may need and this is often what prevents us from

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getting the services that we so desperately need. It is reported that many times it is the social services worker or caseworker that can prevent some of us from getting benefits. There are also programs or treatments that we cannot attend due to not having the proper benefits. This is a major problem among many of us in New York that inhibits or completely prevents our ability to recover.

Next Steps

This White Paper is a call for action to the Office of Mental Health (OMH), county governments, elected officials and providers to stop talking about what is not working in the mental health system and start focusing on what will bring positive outcomes to people who use services.

As a next step, we identified the need for state and local offices of mental health to collaborate with consumer, survivors and ex-patients for the purpose of developing recovery-focused outcomes and quality indicators based on the ten rules that we have collectively identified as priority. These quali-

ty indicators should be interwoven through the Evidence-Based Practices (EBPs) initiatives and offered as a recommended framework or foundation for all OMH licensed and operated programs.

Additionally, the development of instructional and/or collaborative tools that would help operationalize our rules into practice would be a way to move beyond talk towards action. For example, an interactive computer tool might be created that would assist a person who is using services in making informed treatment decisions with his or her service provider. It is our deepest hope that state and local governments will also use this as an opportunity to create a new vision that looks at a culture of wellness and the elimination of discrimination and coerciveness.

This document is just the beginning of a very important movement. This process has left many people eager to get involved in participating in a collective effort to change the mental health system and improve the quality of life for so many New Yorkers by bringing the promise of a better future. It is our sincerest hope that all stakeholders will rise with us to meet this occasion.