

**Nebraska's Consumer Voice:
Leading a Change in Mental Health Services**



Mental Health Association of Nebraska

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April 2009

Acknowledgements

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ABSTRACT

The information provided in this paper is the collective voice of mental health consumers from all behavioral health regions in Nebraska, and is a result of our experiences within the system. It is a movement toward infusing recovery principles into Nebraska's mental health service delivery system that will guide individuals toward Self-Help, Self-Determination, and Empowerment. Furthermore, this is an attempt to bring all stakeholders, including consumers, providers, family members, and policy makers together to create a new vision of a system that is more Person-centered and Recovery-focused. Through full consumer participation this paper establishes 11 rules to implement into Nebraska's current and future method of Behavioral Health service delivery.

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In 2001 President Bush called for a “New Freedom Initiative” to address and eliminate inequality in the access and availability of education, health care, and employment services for people living with mental and/or physical disabilities. Stigma, unfair treatment, financial limitations on mental health benefits, and fragmented service delivery were all identified as obstacles to receiving quality care for Americans living with mental illness (*Achieving the Promise, Final Report, 2003*).

Under the *Initiative*, *The New Freedom Commission of Mental Health* was created with the objective of identifying areas of mental health services which need improvement, so as to facilitate quality treatment for both adults, and children living with mental illness. This included making concrete recommendations for state, Federal and local agencies as well as both public and private providers.

The commission reported that serious mental illness, as defined in the DSM-IV, is a prevalent and serious public health issue affecting about 5-7% of adults and 5-9% of children in a given year. Furthermore, treatment is costly and represents an annual indirect cost of \$79 billion in the United States, \$63 billion of which comes from a loss of productivity. This loss is reflected by the high unemployment rates among people living with mental illness, as it is the number one cause for disability in the United States according to the World Health Organization (2001).

In its *Interim Report to the President in 2002*, the *New Freedom Commission of Mental Health* concluded that “the system is not oriented to the single most important goal of the people it serves—the hope of recovery”. (*Achieving the Promise, Final Report, 2003*). According to the Executive Summary of the report, the Commission received feedback, comments and suggestions from about 2,500 recipients of mental health services, from all 50 states between June of 2002 and April of 2003. This report laid the foundation for a national change toward recovery-based practices in the mental health system.

In July of 2003, *The Presidents New Freedom Commission on Mental Health* concluded the mental health system in America is fragmented, and broken, and must be transformed. The report identified the following six goals for transformation:

1. Americans Understand that Mental Health is Essential to Overall Health
2. Mental Health Care is Consumer and Family Driven
3. Disparities in Mental Health Services are Eliminated,
4. Early Mental Health Screening,
5. Assessment, and Referral to Services are Common Practice,
6. Excellent Mental Health Care is Delivered and Research is Accelerated, and Technology is Used to Access Mental Health Care and Information.

These goals would be the guiding principles for a national transformation in the mental health system.

INTRODUCTION

In 2004, Nebraska began a Behavioral Health Reform in an attempt to achieve the goals set forth by the President's *New Freedom Commission on Mental Health*. At the heart of its mandate is LB 1083(2004), a bill which calls for community-based services that are "research based and recovery focused," and emphasize beneficial treatment outcomes of recovery". In 2006, the Nebraska state legislature clarified LB 1083(2004) by adding additional language concerning consumer involvement in LB 994 (2006). The new statute called for consumer "inclusion and involvement in all aspects of services design, planning, implementation, provision, education, evaluation, and research" (LB 994, 2006).

The Mental Health Association-Nebraska (MHA-NE) received a multi-year consumer networking grant with the intent to transform Nebraska's current mental health system. MHA-NE is a consumer run and directed education and advocacy organization. As direct recipients of mental health services, we would like people to hear what consumers have to say about the system. Working together as partners in our treatment we will be able to get back to productive lives in the community.

In order to facilitate the process of implementing consumer input at all levels of planning, MHA-NE consulted executive director Steve Miccio, of PEOPLE, Inc (*Projects to Empower and Organize the Psychiatrically Labeled*). Miccio compiled and edited, *Infusing Recovery-based Principles into Mental Health Services* (2004) in an effort to collect recommendations from New York State consumers, survivors, patients and ex-patients how New York State could create recovery-based services. The *Institute of Medicine Quality Chasm: A New Health System for the 21st Century Report* (2001) stated, "The health care delivery system has floundered in its ability to provide consistently high-quality care to all Americans." This report set a starting point for Miccio who used the recommendations for change in health care service delivery:

1. Care based on continuous healing relationships
2. Customization based on patient needs and values
3. The patient as sole 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(*The Institute of Medicine Quality Chasm: A New Health System for the 21st Century Report*, 2001)

Following Miccio's lead, MHA-NE similarly used the recommendations above as a starting point for a mental health system transformation project, *Recover Nebraska*. In addition to these recommendations, MHA-NE used the ten fundamental components of recovery identified in SAMSHA's National Consensus Statement on Mental Health Recovery (2006) as a platform for discussions guiding *Recover Nebraska*. These ten components of recovery are Self-Direction, Individualized and Person Centered, Empowerment, Holistic, Non-Linear, Strength-Based, Peer-Support, Respect, Responsibility, and Hope, all of which were later incorporated to the project.

METHODS

Part 1

Recovery Self Assessment

The Recovery Self Assessment (RSA) Surveys (O'Connell, Tondora, Crogg, Evans & Davidson, 2003) was used to collect baseline information from all Mental Health stakeholders, who include: consumers, providers, agency directors, friends and family members, each of whom received an audience specific survey. Copies of the RSA were given to agency directors at regional provider meetings and mailed to 87 agencies state wide. The self-report survey consisted of 36 items that reflect practices associated with recovery. Participants rated responses on a 5-point Likert scale from (1) strongly disagree to (5) strongly agree.

The survey included the following five empirically designed subscales

identified by O'Connell, et al. Croog, (2003).

Diversity of Treatment Options: 10 questions reflect the extent to which an agency provides options such as: peer mentors and support, a variety of treatment options, and assistance with becoming involved in non-mental health/addiction activities in the community.

Consumer Involvement and Recovery Education: 7 questions reflect the extent to which persons in recovery are involved in developing new programs/services, making provisions to existing programs, providing staff trainings, involvement in advisory boards/management meetings and community education trainings.

Life Goals vs. Symptom

Management: 6 questions reflect the extent to which staff helps with the development and pursuit of individually defined goals (education and employment).

Rights and Respect: 6 questions reflect the extent to which staff refrains from using coercive measures, provide consumers with access to treatment records, and facilitate outside referrals.

Individually-tailored Services: 7 questions reflect whether the services an individual receives focus on individual needs, culture, interests, provided in a natural environment, and focus on building community connections.

Findings

Of persons surveyed, 27

Directors/CEO's, 215 providers, 359

persons in recovery, and 47 family/significant other/advocate make up a total of 649 responses to the RSA received from 27 different agencies. Results of the RSA identified areas of success and areas in need of improvements. All groups and regions had similar responses to the five subscales. Results from participants showed Agencies were rated highest on *Rights and Respects* by all participants. *Consumer Involvement and Recovery Education* received the lowest rating from all participants.

Part 2

Follow up: Recovery Education Workshops

The RSA survey responses identified Consumer Involvement and Recovery Education in Nebraska as a top priority in need of change. As a first step towards Involvement and Recovery Education MHA-NE's consumer facilitators conducted recovery education workshops in all areas of the state. Starting in 2008 MHA-NE began Recovery Education presentations with consumers of mental health services by travelling throughout all six Nebraska regions. Within the year 20 presentations were given, 12 to consumers and 8 to providers. A combined total of 234 individuals participated in the consumer meetings. 186 individuals made up the combined total of provider participants.

After discussions at recovery education workshops it became evident that consumers in Nebraska did not have a voice. To help achieve this voice, MHA-NE further engaged, consultant, Steve Miccio.

Following Miccio's recommendations, The *IOM's Crossing the Quality Chasm Report* (2001) was used as a guideline in preliminary dialogues. This is not intended to take away the current system of care but is to have the recovery model implemented in all areas of service delivery.

From these meetings, a draft of rules was created that would be specific to mental health care in Nebraska. These new rules became the focus for dialogues with participation from over two hundred people. The content of these dialogues was then summarized and brought to three hundred additional people for their reactions and input. After input was given, comments were tabulated and ranked in order to determine importance.

RESULTS

All rules are equally important however the rules are listed in prioritized order.

The Rules for Quality Mental Health Services in Nebraska

- 1. Transportation barriers must be eliminated**
- 2. It must be recovery focused**
- 3. There must be access to services**
- 4. There must be peer provided services**
- 5. There must be access to complete medical records**

6. Care must be based on a partnership between consumer and provider
7. There must be access to affordable housing
8. There must be more recovery education
9. There must be opportunity for competitive employment
10. There must be access to information regarding benefits
11. Do no harm

DISCUSSION

Nebraska's Mental Health Reform has created an interest and call to action to infuse input, our input, into the current methods of mental health services throughout Nebraska. This is our opportunity to create a vision of recovery. The state has had a number of successes in its service transformation including the expansion of community-based treatment and employment services. Unfortunately, the majority of all these activities have been designed, developed, and implemented with little or no consumer involvement. What involvement did take place, was limited to advisory input only, and requested after official decisions had been made. This is in direct conflict with mandate designated by Nebraska LB 994 (2006) which called for direct participation from consumers in all phases of the reform.

This paper, takes the fragmented ideas from people who are recipients of mental health services in Nebraska, consumers, who live in every region of Nebraska and paints a clear picture as to what quality, recovery-based services look like. The National Association of State Mental Health Program Directors and the National Threat Assessment Center ({NASMHPD/NTAC}, 2004) uses Dr. Ruth Ralph's definition of recovery "as a process of learning to approach each day's challenges, overcome our disabilities, learn skills, live independently and contribute to society. This is supported by those who believe in us and give us hope".

Many advocates for mental health recovery services believe that the existing mental health service delivery system "has failed to facilitate recovery of most people labeled with severe mental illnesses, leading to increasing expressions of dissatisfaction by people using services, their families, and administrators. Only a fundamental change of the very culture of the system will ensure that the changes made in policy, training, services, and research will lead to genuine recovery" (Fisher & Chamberlin, 2004).

We believe that to truly affect system change in Nebraska these recovery principles must be implemented into the current system of service delivery. The rules outlined in this white paper are in essence a call to arms for providers and consumers to break down barriers that have prohibited individuals to live productive lives in

the community with the idea that recovery is the expectation. Individuals will be treated with a holistic approach and move toward a life full of hope and wellness.

Throughout this document you will find a common theme; the relationship that exists between persons who utilize mental health services in Nebraska and provider. You will also see how the power of listening can help those of us with a mental health diagnosis gain invaluable hope through knowing that our feelings are valued, we are respected, and we are listened to. Recovery begins with being listened to as it helps us build a sense of trust and creates a feeling of belonging in the community.

We believe that recovery is an individual process and the path has to be determined by each person as recovery is a non-linear process. This white paper is not intended to define recovery but rather to focus on the individual and not just symptom management. There are many known philosophies, guiding principles, and beliefs based on scientific and anecdotal evidence that promote and support recovery but there is no one size fits all solution. It is our hope that these simple rules identified by those of us who have first-hand experience dealing with Nebraska's behavioral health system will help people understand how to support someone in their recovery.

"I have no way of getting to doctor appointments with no income."

RULE 1: Transportation Barriers Must Be Eliminated

Poor people can't always afford to get to treatment facilities. Why would we expect a good show rate for appointments?

There are a variety of issues, and barriers in regard to transportation. We have experienced the following issues in response to transportation and how it may affect our recovery.

- The need for increased access to transportation
- Hours of service/limited
- Cost
- Reliability of service
- Geographic availability (routes and rural)
- Health care issue-no transportation subsidy
- Knowledge base education for providers and consumers around transportation
- Transportation for non-traditional services i.e.- peer support, 12-step programs

Hours of services limited-In some rural areas there is no transportation at all such as Alliance, Chadron, etc. In areas where there is some public transportation there is inconsistent service in the evenings, weekends, and on holidays. This can inhibit recovery if a person is working and can't get to work or home due to lack of transportation. Some people would be willing to

use natural supports such as friends or family members to get to appointments or work. The handy bus in many areas requires a 24 hr notice to receive transportation. Feeling stuck without transportation when help is needed gets in the way of our recovery and can cause symptoms to increase and possibly a full-blown crisis.

Cost-Many people are living at or below poverty level, and the cost for transportation hinders our quality of life. Some of us attempt to pay for transportation which can result in a poorer quality of life or hardship.

Reliability of Service-When people access transportation they often are late due to the transportation service being unreliable i.e. taxi's. If a third party schedules transportation such as Health and Human Services (HHS) or case managers there are times when that information does not get to the person in need of the transportation, resulting in a missed appointment.

Geographic-There is a need to increase transportation throughout all counties that would allow us to live a more self-determined independent life that can include community, work, and appointments. It is important to be able to meet with providers in person.

Healthcare-For many, mental health insurance only pays for transportation to mental health appointments. With the evidence of people with serious mental illness dying twenty-five years earlier than the general population we are asking for urgency around

providing health transportation as well.

Knowledge based education for providers and consumers-We believe that the professionals in the mental health community should be aware of all transportation programs and should help educate consumers about accessibility. There should be training programs that teach consumers how to access public transportation and all of the processes regarding successful transportation, such as: paying for a ticket, how to pull the chord to stop the bus, where the bus stops are, how to read a route map, how to transfer, etc.

Transportation for non-traditional services-Transportation for non-traditional services such as advisory committee meetings, peer council, peer support and 12-step programs, drop-in centers/clubhouse, social groups, etc. This promotes recovery by empowering us to seek new ways of becoming self-determined and helps us to learn more about others ways of recovery through a peer network.

Rule 2: It Must Be Recovery Focused

Many of us have experienced punitive care for our thoughts and behaviors, such as attempting to reduce our medications or trying new things and being told not to by our mental health provider. Our illness is often treated with increases in medication or treatment when it is not what we think is in our best interest.

Many of us would like to have the freedom to experience risk and make

decisions that promote better recovery outcomes. We are asking for support in our decisions that we believe are in our best interest. We would like to be involved in our treatment plans and respected as a partner with our treatment provider. We would like to be asked about what we think would be helpful in our own recovery. This is a request for more person-centered care based on our individual needs and choices that foster our responsibility within recovery.

By understanding our rights we are more self-determined to make informed choices in our treatment. We would like to know that we can disagree or refuse treatment in a respectful manner and be offered alternative choices that we can choose.

We want to feel empowered and comfortable to ask questions about our treatment without fear of retribution. Having a mental health diagnosis does not make us incompetent. We are intelligent and capable of processing and evaluating information to make our own decisions about things that affect our lives that affect our recovery.

We want to feel hopeful towards recovery rather than hopeless when faced with our issues and we would like to hear encouragement from our treatment providers rather than “can’t do” language and attitudes.

We would like help in learning and understanding all options that may help in our recovery in addition to

transitional mental health treatment, such as natural supports, peer supports, education, and encouragement around community events that may be of interest.

We would like to have the ability and support to learn from our failures through personal experience. We agree that being prevented from taking risks prevents us from learned success and failure.

We would like the opportunity to develop wellness plans and crisis plans that are respected and help us to learn ways to prevent crisis or see crisis as an opportunity to learn and grow through recovery.

Rule 3: There Must Be Access to Services

We would like to have access to services 24/7 other than hospitals or crisis centers. We would like access to alternative services and to see extended hours in all services.

We would like to choose our own providers and have the ability to change providers as we see fit. As we choose we would like to do it freely with our fear of retribution or negative consequences.

As it currently stands if you want to change doctors and try while under emergency protective custody the doctor will write the mental health board so you don’t have a chance to change doctors and may end up in a

“Encourage me to locate/utilize natural supports.”

more restrictive setting. Coercion is used.

We would like to have access to services regardless of ability to pay.

We would like to have more access to dental care. Many dentists in Nebraska do not accept all insurances including Medicaid.

We want to eliminate waiting lists for treatment and if we have been discharged from treatment we would like the opportunity to re-engage without waiting if needed.

We would like immediate access to dual diagnosis treatment rather than being seen for one illness before being permitted to be treated for the other illness or addiction.

We would like to be able to obtain information about our community resources for housing, transportation, employment, treatment, health care, alternative treatment, food pantries, community services (libraries, art, etc.), education, faith-based, etc.

Rule 4: There Must Be Peer Provider Services

We would like to see more peer run services in all of our communities such as:

- Drop-in Centers
- Warm Lines
- Social events/Activities
- Advocates in Hospitals, Clinics, and Mental Health

Programs

- Trainings

Peer Advocacy

Peer Networking

Wellness and Recovery

Wellness Recovery

Action Plan (WRAP)

Leadership Training-

Leadership Academy

- Hospital Diversion
- Peer Companions

We would like to see the integration of peers working in traditional mental health settings as respected staff with the goal of promoting a more recovery based approach.

When asked what he needed when he was going through tough times, he replied, “I don’t know how to answer that question, nobody has ever asked me that before.”

We would like to have access to support groups in the community.

Being active in the community and extracurricular activities is vital to our recovery. We would like to see more free/low cost options.

Rule 5: There Must Be Access to Complete Medical Records

We would like to see more accurate, detailed information in our medical records. Often there is only one

sentence used to sum up a whole appointment. This is causing insurance companies to put limits on session times (10 min. vs. 20 min. med checks) and the whole picture of what is going on is not seen.

We would like free access to our medical records that are not redacted. We would like to be able to see our records immediately and receive copies for free. We want the right to change our records if they are inaccurate or incomplete. We would like the freedom to read our records in private.

Rule 6: Care Must Be Based on Partnership between Consumer and Provider

We would like to be equal partners in our treatment. That means we want to be listened to and validated in our decisions, hopes, dreams, and goals. We want to be seen as credible reporters and experts in our own care. As we develop treatment plans in partnership with the therapist, doctor, or other medical providers we want frequent plan updates that are person-centered and holistic. Please do not try to “fix” everything about us with psychiatric medications.

We want providers to conduct more testing when determining a diagnosis rather than just adding a label after a 10-15 minute appointment.

We would like to see all of the different treatment providers work better together in terms of good communication and information sharing so that we do not have to tell our stories over and over.

In working with our providers we would like to be fully informed about our medication including short and long term side effects so that we can make informed decisions about our care.

We would like to be given more information regarding the medications we are prescribed (how medications work, what we can expect, how we will be able to tell if it is working, interactions with certain foods, etc.).

We would like better communication between pharmacies and labs. Some medications require monthly blood draws and lack of communication can mean missed doses.

We would like to have information about physical health problems that are often caused by side effects of psychiatric medications including early warning signs, prevention, and tips.

When working with case management we would like to be given options on where to live rather than be “placed” regardless of our condition.

Rule 7: There Must Be Access to Affordable Housing

We would like to have affordable housing out in the community. A lot of us have experienced trauma and it is important in our recovery to have a comfortable place to call home in a safe neighborhood.

We want to see an end to discrimination by landlords regarding people with disabilities. We agree that there are some really good

landlords but that there are some who take advantage of disabled people. Sometimes landlords do not fix things in a building/apartment as promptly as they normally would when rental assistance is provided because they know they will always get the rent on time.

For many of us pets support us in our recovery. Most apartments who accept public rental assistance do not allow pets even if they are trained as pet therapy animals. We would like to have more options when looking for places to live so we can keep our pets.

We would like to receive more information about housing programs including where to apply, qualifications to be approved, how long the waiting list is, etc. We want to see more programs created to help with deposits and start-up fees when transitioning from one living arrangement to another.

Some of us may feel more comfortable when working on our recovery if we are living in a group home or

an independent living situation with supports. However, the cost sometimes prevents us from being financially secure. We would like to

have the opportunity to move into a living situation at our own place. We don't want to be sentenced to a living arrangement for life because others around us believe that it is the only or best option.

"Please don't discourage my dreams because you (the case worker/therapist) think it is too much work for you."

We would like to be given the freedom of choice even if it involves some risk.

Rule 8: There Must Be More Recovery Education

We feel there is a high need for recovery education in every area of the state. Most trainings are held in Lincoln and Omaha which prevent people from other areas to benefit from the trainings. All stakeholders including policy makers, providers, consumers, and friends/family members need to be more educated on the recovery model and need to learn the differences between wellness-based services and illness-based services. We would like to see more recovery and stigma/discrimination trainings offered to law enforcement and persons working in the judicial system. Frequently arrests are made when the problem is really a mental health issue.

We would like to see wellness and recovery principals taught in the education system beginning in junior high/middle school. College psychology courses need to be teaching the recovery model and teaching alternative therapies to new graduates entering the field. This education will help create a paradigm shift that will eliminate or reduce stigma.

For many of us spirituality is a big part of our recovery and is part of a holistic approach. We are asking that our beliefs be respected and providers become aware of differing cultures, ethnicities, belief systems, etc. We would like to see up to date training

for all mental health workers. This can include: in-services, workshops, newsletters, teleconferences, and webcasts. We would like to be involved in these trainings by telling our stories through our eyes. This will offer opportunities to be listened to and empower us and give us hope.

So many times we have been told we can't do things including getting back into the workforce or furthering our education. There need to be more opportunities to help people with education and employment throughout the entire state not just in specific areas.

We want to have the opportunity to further our education and would like to see supported education programs implemented in all areas of the state. We would like to see more programs established that teach us basic life skills-cooking, budgeting, cleaning, laundry, how to apply for a job, etc. which would improve our recovery and quality of life by giving us the knowledge to live full/productive lives in our communities.

Rule 9: There Must Be Opportunity for Competitive Employment

Most of us would like to be given support to go back to work. Someone stated, "I like working, feeling useful, and giving back to the community." We want to participate in competitive employment opportunities. We would like to be asked what kind of job we are interested in and not have to settle for menial jobs (dishwashers, clerical, cleaning crews) or jobs carved out for us with very low pay. There is still a

lot of stigma/discrimination in some workplaces.

Sometimes we need support when going back to work. Many of us have been told for so long "You can't go back to work or you will lose your benefits". Providers and consumers need to have access to information about benefits because not all assistance will be taken away. We want all the information up front so we can make an informed choice about whether working would cause more of a financial hardship. There are some new programs that we can utilize that prevent us from losing our medical insurance. People do not know enough about these programs so there need to be educational opportunities to learn especially when we are working with a lot of different agencies.

Obtaining a benefits' analysis is vital to our recovery when we are returning to work or already working and must be accessible and readily available. It currently takes a long time to receive a full benefits analysis so we often have to turn down job offers and promotions because we do not have the information to make an educated decision about how our lives will be affected.

Many of us can not afford the internet at home or do not know much about computers so searching and applying for jobs is difficult. If we do attend day programs often they have computers available for use but some of us need or want training on how to use them.

Many of us have had to take a break from work so there are gaps in our resumes, or we may have forgotten how to fill out applications. Supported employment has been a successful program in Lincoln and is an evidence-based practice. We would like supported employment programs across the state.

Going back to work for many of us means regaining control of our lives, taking personal responsibility, and more independence. Our quality of life improves as we are able to afford to participate in more community activities and things we enjoy. Employment increases our self-esteem and confidence, and helps us feel like valuable individuals in our communities.

Rule 10: There Must Be Access to Information Regarding Benefits

It is our experience that there exists a lack of knowledge in the professional mental health community and consumer community around benefits. We have experienced obtaining inconsistent information about how to qualify for benefits as well as how employment may affect our benefits.

The benefit services offer inaccurate information as well and this creates a hopeless scenario for many of us that have taken the time to explore seeking better outcomes.

We would like a simplified guideline to understanding all benefits so that we can make better decisions for our future. Better education would consist of

the following:

- SSI
- SSDI
- Food Stamps
- Vouchers for services
- Medicaid/Medicare
- Employment
- Housing
- General Assistance/AABD

We would like to end the confusion surrounding benefits and not think of going back to work as a disincentive towards recovery.

We would like to understand how we can begin recovering and “Do better” and keep our medical benefits as we progress. High medical bills prevent us from moving to an improved socio-economic status. This is a barrier to our independence, self-esteem, and recovery.

We feel that being turned down for benefits not only hinders our recovery but also affects our overall health care. We also want a more efficient process that cuts the approval time down dramatically so that we can worry less about our benefits and focus more on our recovery, hopes, and dreams.

We want to see everyone have access to affordable healthcare with mental health parity.

Many of us use medication as a tool in our recovery.

“Don’t stick me in a very small room with no one to talk to for hours and hours when I am not feeling well.”

Due to the high cost of healthcare and insurance, there are often restrictions put on medications we take. We are not opposed to taking generic medications or trying lower cost medications as long as it does not cause more harm. Some generic and older medications cause more side effects and are not as effective in reducing symptoms. If the substitute medication given does not work for us we would like to be allowed to change without additional cost.

We are not opposed to getting off of our benefits as long as it does not create additional or undue hardship. When determined a payee or guardian is needed we would like to have the option to change if needed. If we have a payee we would like to be given the chance to be our own payee when we feel we are ready. If it doesn't work we would like to be allowed to go back to our previous payee.

Rule 11: Do No Harm

We want all service providers to be trained in trauma-informed care. Many of us are victims of trauma experiences and at times formal treatment has been traumatizing. Trauma-informed care will ensure compassionate, empathetic care that doesn't inflict further harm. We would like to see the reduction and elimination of seclusion and restraints. We would like to see the development of a grievance process that is independent and fair with quick and efficient resolution.

Please look at our skills and abilities not our disabilities.

CONCLUSION/NEXT STEPS

As a next step, we identified the need for the Nebraska Office of Consumer Affairs, county governments, elected officials and providers to collaborate with consumers of mental health services to design a vision and implementation plan to include the culture of wellness, eliminate discrimination, and increase transparency to transform the state's present model of care, the medical model, to one that follows established recovery principles.

We would like to see positive changes that will lead to positive outcomes of individuals who use services.

We would like to see the eleven rules that we have collectively identified as priority. These rules we identified collectively as priority should be interwoven into existing mental health services and offered as a recommended framework for new and upcoming programs.

This paper has given the voice to many consumers and is just the beginning of a very important movement. Most importantly we would like to improve the quality of life for so many individuals in Nebraska. It is an opportunity to provide people hope for their future. It is our wish that all Nebraskans will band together to support this effort.

"This is the first time I got to express myself in 14 years. I want to get my own place."

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