

**CQI Quality of Life
Needs Assessment Report, 2003**

Consumer Quality Initiatives, Inc.

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Table of Contents

EXECUTIVE SUMMARY	4
SURVEY METHODOLOGY	5
CQI	5
INTERVIEWERS AND INTERVIEW PARTICIPANTS	5
THE INSTRUMENT	5
DEMOGRAPHICS	6
RESULTS	9
QUALITY OF LIFE RATINGS ON THE DELIGHTED/TERRIBLE SCALE	9
GOOD STRETCH	9
Description of Good Stretch	9
How to keep well during Good Stretch	12
End of Good Stretches: How life fell apart	12
Preventing Breakdowns	14
BAD STRETCH	15
Description of Bad Stretch	15
Services used during Bad Stretch	16
Recovering from Bad Stretch	17
Ending Bad Stretch sooner	19
COMPARATIVE ANALYSIS	21
DISCUSSION	22
RECOMMENDATIONS	23

1

Executive Summary

- CQI used a semi-structured survey instrument to interview 27 MassHealth recipients about particular “good stretches” and “bad stretches” of mental health. All had been hospitalized psychiatrically at least once in their lives, with two-thirds hospitalized in the past year and about a quarter hospitalized in the last month.
- Almost two-thirds of the survey respondents were female. Respondents ranged in age from 26 years to 63 years, with a median age of 41 years. About three-quarters identified themselves as “Caucasian or white”. Half of the respondents listed bi-polar disorder as their primary diagnosis with almost a third listing either a schizoaffective disorder or schizophrenia as their primary diagnosis.

Good Stretch

- Description: Respondents tended to describe their good stretches in terms of their productivity, their sense of happiness, having a sense of hope, or a combination of these things. When asked to define the good aspects of their lives during these good stretches, half talked about employment being a key factor while a quarter identified satisfying housing as a contributor.
- Activities: All participants said they had engaged in some activity on a regular basis during their good stretch.
- Maintenance: Approximately half of the survey participants said they were able to maintain their good stretches by being busy and/or practicing some form of self-care. Others mentioned prayer/spiritual activities or treatment supports, including therapy, as significant factors in maintaining their good stretches.
- Ending: When asked what led to the end of the good stretch, more than two thirds of respondents pointed to the loss of someone through the breakdown of a relationship, death, illness or separation. Almost one quarter of respondents identified job related stress as the precipitant of the end of their good stretch. Similarly, about one quarter mentioned discontinuing their medications as playing a role or causing the good stretch to come to an end. Some could not cite an event or cause for the end of their good stretch, accepting it as part of life. A few respondents stated that their good stretch came to an end as a result of a decline in their health or the loss of their apartment.
- Prevention: When asked what could have prevented breakdowns, respondents talked about improved job supports, good therapy, and medications. Many respondents did not think anything could have helped or had unspecific ideas.

Bad Stretch

Quality of Life Report

- Description: About half of respondents described deep feelings of depression when asked about their bad stretch, many saying they had been suicidal. Other feelings included anger, isolation and a lack of confidence in themselves and others. Many talked about difficult circumstances with housing, unemployment, hospitalizations, severe symptoms, substance abuse and overwhelming events.
- Ending: When asked what got them out of their bad stretch, one-third of respondents referred to changes in their medications, one-third talked about community mental health services funded by DMH or Medicaid, and one-quarter talked about peer support. When asked what personal characteristics helped them get out of the bad stretch, almost one half of respondents referred to their perseverance.
- Ending earlier: Almost half of respondents said that nothing could have helped them end their bad stretch sooner or that they could not think of anything that would have helped. Other respondents said that going into a particular kind of treatment earlier, receiving better access, quality or a new type of service, might have helped. Others thought that more peer or financial support would have helped to end their bad stretch sooner.

Multiple Hospitalizations

- Those with the most frequent hospitalizations were most likely to feel hopeless during their bad stretch and not have any ideas of what might have gotten them out of their bad stretch sooner than they did.

Recommendations

- Motivational Interviewing is a useful tool for therapists to help consumers gain greater insight into their condition and the role of medications in their lives, and ultimately help them to be in a better position to avoid crisis.
- The Wellness Recovery Action Plan (WRAP) is a crisis prevention wellness methodology for consumers to work together to identify triggers/stressors that might destabilize them and to develop prevention strategies.
- Medicaid and other agencies might work better together to connect acute services to rehabilitative (eg., employment, housing) supports.
- The Recovery Learning Center is a proposed method of the Consumer Family workgroup to help consumers develop independent living skills and support networks, that would include assisting them with finding and maintaining housing, jobs and healthy relationships.
- Incorporation of strategies to help people with histories of significant trauma will go a long way to reducing high frequencies of hospitalizations.

2

Survey Methodology

A. Consumer Quality Initiatives

CQI's written mission is to "give consumers a greater voice and an integral role in evaluating the effectiveness of their [our] treatment" through "fair, honest and balanced" reports on consumer perception of quality and satisfaction. CQI provides a forum for that voice through confidential interviews with clients. Through their mission, CQI hopes to "initiate changes to improve the system for all, consumers and providers alike." The small group discussions about data among consumers, providers and health care authorities are helping CQI to begin bridging information gaps that establish a common understanding of quality and mental health.

B. Interviewers and Interview Participants

CQI interviewers recruited participants primarily at specified group settings- two clubhouses, a day program, the MBHP consumer advisory council, the Freedom Center (a consumer-run advocacy and drop-in center), HEAP (Homeless Empowerment Advisory Project) and a young adult housing program. At some sites, CQI offered to pay the site \$100 if they could produce 4-5 people who would engage in the interview. At a few of these places consumers were paid \$25 directly for their participation. In addition, CQI was interviewing DMH case management clients at the time, and some with MassHealth were offered a chance to participate in exchange for \$25.

The interviewers were consumers of mental health services and family members of consumers, who have received extensive training in interview techniques. Because of their personal experiences with mental illnesses, these interviewers often were able to build a rapport with respondents that would not have been possible otherwise. This rapport appeared to help the individuals who were interviewed to speak openly and honestly about their treatment experiences.

To participate, survey participants must have been able to identify a "good stretch" lasting at least a week (when their lives were going well) within the last five years; similarly, they must have been able to identify a "bad stretch" lasting at least a week (when their lives were going poorly) within the last five years. Participants also had to have demonstrated their ability to reflect on their life experiences from the past through interviews for other projects or more casual conversations.

C. The Instrument

The CQI "Quality of Life Needs Assessment Survey II" offers respondents an opportunity to talk for approximately 45 minutes about their current quality of life, a good stretch of life and a bad stretch. Interviewers recorded comments and responses to open-ended questions using respondents' own words as much as possible, though longer responses were

sometimes paraphrased. A few of the items included prompts that helped the respondent think more critically about their experiences.

Three of the survey items included a seven-point “Delighted-Terrible” (D-T) scale on which respondents rated their quality of life in different contexts. (Two items required survey participants to rate their lives during their good and bad stretches, and one item required respondents to rate their life “in general.” .) CQI borrowed the D-T scale from the Anthony Lehman’s Toolkit for Evaluating Quality of Life, which is available for public use. The scale’s points ranged from “Delighted”, with a value of 7, to “Terrible”, with a value of 1. Points 2 through 6 were labeled “Unhappy”, “Mostly Dissatisfied”, “Mixed (about equally satisfied and dissatisfied)”, “Mostly Satisfied”, and “Pleased”, respectively.

3	<i>Demographics</i>
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CQI interviewed 27 individuals about their quality of life. Almost two-thirds (63%) were female. The participants ranged in age from 26 years to 63 years, with a median of 41 years. A majority (74%) identified their race as “Caucasian or white,” with 15% “African American or Black” and the remainder multiracial or Native American. Three persons (11%) reported having Hispanic ethnicity. All but one person (Creole) said that their primary language was English. Approximately three-quarters (77%) of respondents reported being heterosexual, 15% gay/lesbian, 4% bisexual and 4% asexual.

Life Circumstances:

Seven people said they were working for pay (either full or part time) with the remainder not working, volunteering or declining to respond. Participants’ varying educational levels and housing situations are included in the tables below:

Highest Level of Education	Percent (n=27)
8 th grade or less	4%
Some high school	22%
High school graduate/GED recipient	15%
1 to 3 years of college	18%
College graduate	41%

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Housing Situation	Percent (n=27)
Live alone	45%
Live with spouse/significant other	22%
Group or nursing home	15%
Roommates	7%
No Stable Address	7%
Family	4%

About half (56%) were single and never married, with 20% married or living as married, 16% divorced, and 8% widowed (N=25). One-third had children.

Primary Source of Emotional Support	Percent (n=27)
Family or Significant other	30%
Therapist	19%
Case Manager	11%
Friend(s)	14%
Other	18%
No One	7%

The respondents who mentioned other as their primary source of emotional support listed AA, clubhouse, HRO at group home, staff at program, psychiatrist or supported housing advocate.

Health Care Related

All respondents had MassHealth, with just over half covered by a managed care plan (mostly MBHP, but one person had an HMO), and the remainder covered by Medicare, so that their MassHealth care is not managed.

Self Reported Health Insurance	Percent (n=27)
MBHP	52%
HMO	4%
Fee for Service	44%

Respondents were asked to rate their own physical health at the time of the interview. Almost half (48%) rated their health *good* or *excellent*:

Quality of Life Report

Physical Health Ratings	Percent (n=27)
Poor	0%
Fair	52%
Good	37%
Excellent	11%

Almost one-half said that their primary diagnosis was bipolar disorder:

Primary Diagnosis	Percent (n=27)
Bipolar disorder	48%
Schizoaffective	15%
Schizophrenia	15%
Major Depression	7%
Other (PTSD, Personality Disorder, “Emotional Difficulties”)	11%
Decline to answer	4%

All had been hospitalized psychiatrically at least once in their lives, with two-thirds having been hospitalized in the last year, and 27% in the last month.

Number of Hospitalizations in last year	Percent (n=27)
None	33%
Once	18.5%
Twice	18.5%
3-6	18.5%
9+	10.5%

In the month prior to the interview, people had received the following types of services:

Service	Percent (n=27)
Inpatient	27%
Talk Therapy	85%
Medication Management	85%
Crisis/ER	37%
Day Treatment	26%
Peer Support	67%

4	Results
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A. Quality of Life Ratings on the Delighted-Terrible Scale
(Questions 2, 4, 10, 15)

The following table shows respondents’ quality of life ratings in several different contexts:

Context	Delighted	Pleased	Mostly Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible	N
Life in general	4%	15%	37%	30%	7%	4%	4%	27
Life during good stretch	33%	33%	30%	4%	0%	0%	0%	10
Life during bad stretch	0%	0%	4%	8%	11%	15%	62%	9

A large majority (85%) said that their lives in general had at least some degree of satisfaction. Respondents tended to see the effects of the bad aspects of their lives with more intensity (about two-thirds saying it was terrible) compared to the good aspects (33% said “delighted”).

B. Good Stretch

I. Descriptions of Good Stretch
(Question 2)

Good stretches lasted between 1 week and 2.75 years, with a mean of 8 months and a median of 4 months.

Consumers were asked how they felt during their good stretch. The large majority talked about their productivity and/or their sense of “happiness”. In fact, eleven people used some version of the word “happy”, while others used related terms (“peace” “relief” “beautiful”). One person who had moved into an apartment after being homeless noted: *“I was feeling it was about the good things that happened to me. I felt good inside, I felt happy.”*

As for productivity, people talked about their sense of pride that they could *“actually accomplish things.”* This was often expressed in terms of employment, increased capabilities, and the notion of “hope”:

Quality of Life Report

“I felt good about myself, I could sell myself in the job interview. I had more patience and was feeling more useful- I had my necessities under control so my problems didn’t seem to loom.”

“I was in grad school; confident, enjoying life, enjoying talking to other people, doing the things I like doing- basketball, going out, watching movies. Learning new things, I felt like I was doing something important. A lot of hopefulness for the future. A feeling of life being fun. Being challenged.”

“I was productive, healthy, like I had a good handle on life. I didn’t feel mentally ill. I felt like I had a good relationship with my family. I felt like living.”

“I had feelings of hope, direction, accomplishment and purpose. The sense that ‘I can do this... I can live.’”

When asked what about their lives was good during this stretch, several themes emerged with regard to the person’s life circumstances (only a few referred to their management of symptoms/substance abuse). Close to half of our sample talked about their employment being very important and almost one-quarter talked about the stability in their lives as a result of having housing. Relationships were cited as important by many:

- 1) Good Housing
- 2) Working/employment
- 3) Relationships
 - a. Family
 - b. Lover
 - c. Kids

Representative comments included:

“I was earning a living for myself [store maintenance] and I was told I could have a lot of possibilities. They said they would bear along with my mental illness and be an associate. ... I also attended a couple of functions at Center Club. I thought I would overcome my mental illness and work for myself.”

“I had good friends and was working part-time in a store which helped me feel like a productive part of society.”

“Working at a part-time job, babysitting, friends, kids, helping my mother as needed. Being able to handle all those different things.”

“My father bought me a condo. I had an affair with a man, not a married man.”

“I didn’t go into the hospital. I worked my regular schedule the whole month. Teaching DBT twice a week. Make it to therapy every week. Not self destructive for the month.”

Quality of Life Report

“It was the first time I was able to look past me to see other priorities (my baby). I had just given birth and I was bonding with her and I was surprised by how much I liked having the baby. I liked having a baby; I didn’t mind having to take care of her.”

For a few, stability was the highlight of their lives:

“Things were still up and down, but they weren’t at the point where I was constantly fighting for my services, constantly in and out of the hospital. I had an outreach worker, in a clubhouse. I was in an advocacy class. I just had services I didn’t have to worry about losing.”

“Mostly I was just managing things really well. My moods were not cycling particularly much and I was able to manage my life without feeling I was grasping at straws which is how I normally feel...”

When clients were asked about their activities during the good stretch, there was enough variety so that no one strong theme emerged, except to say that all interviewed were doing something on a regular basis, even if attending a program:

“I didn’t have a day program. I’d go to the Shattuck to meet with my payee and get a shot of Haldol. I’d go to Downtown Crossing to get a cup of coffee.”

“It’s been a very long time since I had a regular schedule. I remember eating out a few times, having sex a couple times. I remember talking to my father who I love very much. Going shopping. Listening to music.”

Services

Treatment	Inpatient	Talk Therapy	Day Treatment	Crisis Services	Medication Management	Peer Support Groups	N
Used during GOOD stretch	11%	70%	22%	26%	70%	63%	27

Treatment	Inpatient	Talk Therapy	Day Treatment	Crisis Services	Medication Management	Peer Support Groups	N
Used during BAD stretch	63%	78%	67%	67%	74%	48%	27

Those in good stretches rarely used the hospital, with about two-thirds using individual services such as talk therapy and medication management, along with peer support groups. Inpatient, day treatment and crisis management care rose during bad stretches, with peer support dropping somewhat.

II. How to keep well during good stretch (Questions 4-8)

Respondents were asked how they stayed well during their good stretch. People's responses fell into the following categories: 1) "Being busy," 2) Self-Care, 3) Prayer/Spiritual, 4) Treatment (medications, therapy).

About half attributed success directly to staying "busy" or "occupied," with some discussing their social networks or day structure (eg., clubhouse), as well as their employment and exercise.

About one-half also talked about their Self-Care capacity in a variety of areas:

- sleep
- sobriety
- physical health care
- exercise
- positive outlook

About one-third talked about attending to treatment supports, such as therapy, but most commonly medications. Several people said that prayer or spiritual activities was a significant or the most significant factor. Illustrative comments included:

"I was doing a lot of really good self-care- physical care, getting up at good times, going to bed at good times, eating well. Working with my providers to find out what was going on with me emotionally. Doing stuff socially and with other people at the office."

"I prayed a lot. I walked a lot. I stayed busy- was always doing something. Moving around. I had my own garden at the time, so I was doing some gardening. I was painting my apartment. Being at my son's made me feel good- cooking for them or having them over."

"I concentrated on the good aspect of things. Conversations that were positive I would pursue."

"The church and bible study were very helpful. I had some close groups of friends that supported me. I did meaningful work and had meaningful friendships."

"I stayed involved in groups. I'd go to Transitions of Boston [clubhouse] three times a week. I go to human rights the third Tuesday of every month. HEAP every Monday."

III. End of Good Stretches: How Lives Fell Apart (Question 10)

Respondents often had rather complicated stories about how their good stretch ended and their lives fell apart, though we really attempted to encourage people to discuss causal features.

(Two people were unable/unwilling to address this issue.) A variety of themes emerged among these 25, with overlap as some identified several interlocking factors/features.

Five talked about **job-related stresses** that caused them to go down hill, and the lack of support needed for them to maintain or overcome their situation. This included taking on a job/promotion that increased their responsibilities, being isolated in a job (physically, or emotionally as a consumer-provider), and losing a job and not knowing how to get it back. In all these cases, employment and related stressors caused symptoms to exacerbate until hospitalization. One person who took on a more responsible job commented: *“My symptoms started flaring up. I think it was because I was working alone. I had mixed feelings about my job and I just wasn’t feeling as good about myself and my life. I lost my ability to concentrate and organize my time and following through with new things.”*

In all of these cases, respondents felt that if there was support either on the job or from outside the job, hospitalizations might have been averted. In addition, it’s clear that none felt they could raise their concerns with their supervisor or understood their rights to request a job accommodation. As the previously cited person noted: *“If I had been assigned a partner at work, that might have made it easier. If my supervisor there had been more familiar with my illness- that could have helped.”*

In four cases, a **death (3) or illness (1)** of a close family member, friend, or group therapy member caused the downfall, facilitated in two cases by the person stopping their medications as a result (with accompanying feelings of responsibility/guilt in two cases). The two people who went off their meds felt that continued therapeutic contact would have helped: *“Going to day treatment and not missing appointments.... More support, maybe from family or friends, might have helped me to do that.”*

In four cases, it was the **breakdown of a relationship** with a spouse or a fiancé that set things off.

In two cases, it was **losing an apartment**. As one person said: *“I was trying to keep my apartment. There was always a problem. I had legal people helping me, but it was starting to fall apart anyway. After a while, they said I was behind in rent. I was going to different organizations to get money, but they didn’t put my payments on the books. I couldn’t please them. It took a year and one-half, but I eventually lost my apartment.”* They basically needed to keep their place.

In two cases, it was problems with their **physical health**. One person felt that his Primary Care Clinician (“PCC”) at the time was not taking her seriously because he had a mental illness. *“I was telling my PCC that something was wrong [lungs] during my good stretch, but they weren’t taking me seriously. I told them I wanted to improve my relationship with them and they told me I was a healthy young woman who needed to see a doctor much less. Ten days later I ended up in the hospital because my lungs had collapsed. My new PCC is horrified by all the comments in the charts of my old PCC who just made me look like a psych patient.”*

Quality of Life Report

In two cases, it was **separation from loved ones**- DSS taking a child and a father's family being in another country. In both cases, neither person felt much could have helped.

Five people acknowledged that **stopping meds** played a role, with two saying it was the causal factor and the others relating it to one of the stressful events noted above. One person commented: *"Counseling... more regularly being counseled could have helped."* Another person noted: *"People told me not to go off my meds and I didn't listen to them. They did try to support me."*

Four people could not cite a causal event, accepting their breakdown as part of life. Comments included:

"I just reached rope's end. I told the staff at the group home to call the hospital and they did. I just got confused mentally."

"It happened gradually. I got depressed... I tried to kill myself. I got in my car and drove to the hospital. Maybe different medications [could have helped]."

In many of these cases, the role of treatment people was significant. A few were less likely to seek help because of the fear of hospitalization. One person was upset about a fight she had with treatment staff. Another felt a major "loss" when her therapist could no longer see her. Others noted that they began to withdraw and lost important supportive contact with treatment people. Suggestions here included more attractive peer-run and respite programs.

IV. Preventing Breakdowns (Question 11)

When asked what kinds of help or support might have prevented them from falling apart, five people said that there was nothing or they could not think of anything. Comments included:

"I don't think that anything could have helped. Everyone did what they could, but I just couldn't handle all of the pain I was feeling."

"People told me not to go off meds and I didn't listen to them. They did try to support me."

Several other people gave uncertain or vague responses. One person [friend died] noted: *"I don't know. I felt pretty low. It would have helped if I could have just slowed down for a while."* Another person talked about greater reliance on "God's governance," and another wished s/he had not "blabbed" about his/her problem in public.

Of those who offered a specific strategy by which their breakdown might have been averted, about one-quarter talked about the importance of staying in therapy or making better use of it. Several others talked about staying on medications, having stronger family connections/supports, assistance with employment (eg., a reasonable accommodation), assistance with housing situations, and in one case more competent treatment from a PCC. A number of people talked about having learned from the experience. Representative comments include:

Quality of Life Report

“[Stopped taking meds] Family- if my mother and father had stuck with me through badness and goodness. Counseling- more regularly being counseled could have helped.”

“If I stayed up with my therapy appointments and had taken my meds, I might not have fallen apart like I did- having to be hospitalized.”

“If I had been assigned a partner at work, that might have made it easier. If my supervisor at ...had been more familiar with my illness.”

“If I had been referred to day treatment [earlier] and if outreach services hadn't been discontinued and started.”

“Recognizing that I was at a really high stress level and I needed to sleep and to eat. I was refusing to eat, too. I needed to be in an environment that didn't have that much stimulation... I'm more careful now.”

“Going to day treatment and not missing appointments. More support, maybe from family or friends, might have helped me do that too.”

“I was telling my PCC that something was wrong during my good stretch, but they were not taking me seriously [made complaints about lungs to PCC] Ten days later I ended up in the hospital in critical condition with lungs collapsed, chest full of puss. ... I was treated as a psych patient by the PCC. My new PCC is horrified by all the comments in my charts from the old PCC...”

C. Bad Stretch

I. Descriptions of Bad Stretch (Question 12)

Respondents' bad stretch lasted from two weeks to one year, with a mean of four months and a median of three months.

When the respondents were asked to describe their “feelings during their bad stretch, about half talked about deep feelings of depression, using words like: “*depressed*” “*worthless*” “*hopeless*” “*suicidal*” “*useless*” “*devastated.*” (Within this group, six people said that they had been suicidal.) Other people also talked about being “angry” (6) or feeling isolated (4). A few people talked about having anxiety, being confused, feeling victimized or paranoid, and feeling weak or tired. One person commented: “*I had a lack of faith in people. I was not able to trust. I thought people were out to punish me even though I did not deserve it. I had a fear of being hospitalized.*” Another person commented:

Quality of Life Report

“I had anxiety and a total lack of confidence. I was paranoid that people were talking about me. A total lack of motivation, feeling tired all the time. Feeling depressed all the time. Not enjoying the things I used to do... Wanting to be alone.”

When people were asked to discuss “what was bad about [their] life during their bad stretch,” responses varied. For several people (6), it was about their housing situation- being homeless, evicted or not liking their residential setting. Three people each said it had something to do with not having a job or being in the hospital. A number of others said it was about an overwhelming specific event- a mother dying, a friend dying, the holidays coming up (eg., Christmas) or the 9/11 World Trade Center attack. A few others talked about being stalked or beat up, using drugs/alcohol, not being able to concentrate, and/or severe symptoms (eg., “hearing voices” “intrusive thoughts”).

Respondents gave descriptions of their daily activities during their bad stretch, with close to one-third saying that they didn’t do much of anything, and their primary activities being “eating, sleeping and watching television,” while remaining largely isolated. As one person commented: *“Just rested, eat, smoke, say a prayer, drink coffee or tea”* Others spent significant amounts of time in respite.

A similar sized group talked about their “maintaining a routine” that involved activities with other people, sometimes as part of their treatment. One person said: *“going to a few meals, attending meetings, going to clubs, going to see my social worker, going to community treatment.”*

Several focused on their involvement in treatment, with Clubhouse attendance as a focus for some. A number of others (5) talked about their overuse of drugs/alcohol” *“A lot of isolation. I was hospitalized.” I started pushing my services aside and not using them like I should have. Marijuana and gambling.”* Three people talked about their employment.

II. Services Used during Bad Stretch **(Question 11)**

Of the 27 respondents, twenty-four used mental health services during their bad stretch at some point. Of the three that did not, one said that he attended a peer support group and the other two said they had not used services or support. As noted above, services were used as follows:

Treatment	Inpatient	Talk Therapy	Day Treatment	Crisis Services	Medication Management	Peer Support Groups	N
Used during BAD stretch	63%	78%	67%	67%	74%	48%	27

A majority had multiple hospitalizations during their bad stretch, while those who had a single hospitalization were in for a week to ten days. Others referred to drop-in centers, advocacy programs or friendship networks.

III. Recovering from Bad Stretch (Question 15 - 19)

All of the respondents told the story of their recovery from the bad time in their lives. They were asked: “What did you do to get out of that bad stretch?”

For one-third, a change in medications (and in one case the use of ECT) was a significant factor, either going back on medications after having gone off them, trying new medications, or having dosages adjusted (lowered). As some noted:

“When I went into the hospital I went back on my meds and was able to really face my feelings and this helped me get back on track.”

“Time and medicine. I think they changed it in the hospital. Talking about what happened.”

“It just happened. My meds were lowered, which always makes me feel better. It’s just a question of not feeling TOO better.”

Just over one-third talked about particular community services funded by DMH and/or Medicaid as a significant part of their recovery; mentioned were crisis services, therapy, clubhouse, respite, case management and medication management. Respondents made comments like:

“I talked with people at Genesis Club and had a community meeting and was able to verbalize that I was feeling overwhelmed and I got support and assistance from other people.”

“I just kept really working with my providers and with my friends trying to figure what was going on and what to do about it. ... At the end, I added other services...”

“I saw my therapist a lot. I talked to her almost daily.”

Several others mentioned the following as key factors:

- Finding a new living place (apartment)
- Being off drugs and alcohol

Quality of Life Report

- Self-help resources (AA, support group)
- Continuing with a routine (work, attending clubhouse/day treatment, school)
- Peer support/friendship (close to one-quarter)

“Finding a place to live helped and having social workers who I was comfortable with helped for support as well.”

“I went to my groups every day. I ate breakfast, lunch and dinner with my friends. It helped me unwind, and the groups every day.”

“It took me a while, but I started to be more social and I got out of the hospital and started to do more things out of the hospital.”

“I guess I started to go out a little and see people again and that helped me feel better. My therapist helped me, too. I know I want to be around people and that helps me feel better. People from Genesis Club came by to see me and told me they missed me and got me to start going again.”

Consumers were asked about the qualities or characteristics that were important for their getting out of bad stretch. (Only one person said that his/her inner qualities did not factor in here.) The most common theme, with almost one-half mentioning it, was **perseverance**, ie, not giving up and making continued attempts to find a way to get better. Terms used were: “Drive” “Not Being a Quitter” “Stubbornness” “Determination” “Persistence” “Ability to fight for the services I needed.”

Several (5) people talked about their **“willingness” to try new things and open up to other possibilities.** As one person noted *“The knowledge to know that there’s more out there for me and I need to be put back on medication and someone would care for me and I felt like I’m better than I thought. I thought I was useless and definitely need meds.”* Another said: *“The ability to ask other people to advocate on my behalf when I felt I couldn’t do it myself.”* Another said, *“Being willing to try again.”*

A few commented on their reliance on spiritual beliefs: *“I went to the Bible, followed my instinct”.* For some others it was the recognition they had to take advantage of the few chances they had: *“My desire to live” “I feel like life is too short.”* Some combined both: *“My belief in prayers and I just believed that no matter how bad things get, you’ve got to survive.”*

A few others commented on their capacity to forgive themselves or others, improved self-awareness, having hope, looking forward, and having strong inner resources. Comments included:

“Knowing that I have an education and wisdom; learning to forgive myself and to look forward for better things and better people.”

“I think I just tried to have a better outlook on life.”

“Sense of humor. Keeping busy.”

People were also asked about the kinds of support from other people or groups that were important for them to get out of their bad stretch, with 88% (21 of 24) saying that this kind of support was valuable. People cited support they received from family (egs., parents, spouses and children), from friends (consumers and non-consumers), and through the mental health system from people they met at residences, in their clubhouses, and at other kinds of consumer advocacy and drop-in centers.

People were also asked about the kinds of mental health services that were important for them to get out of their bad stretch, with 79% (19 of 24) saying that these services were valuable. Nine total referred directly to the guidance they received with **tricky medication issues** (and in one case ECT). As some commented:

“A good relationship with my psychiatrist. He’s pretty flexible, since I’ve been out of the hospital for a certain number of years, he tells me I can raise and lower my medications when appropriate.”

“I took Zoloft for a few months and it took the edge off and that was helpful early on. My doctor was very in tune to my bipolar and she did a good job making sure I was OK. I had good people working with me and they let me part of my own treatment.”

Almost as many (7) referred to a **direct relationship they had with a therapist** with whom they could talk things out. A number of others referred to general and intensive supports such as their case manager, CRS, ICM, residential, VNA and day programs. Three people mentioned referrals to detox/SA treatment.

When asked about other supports not mentioned, people generally did not have a lot to add, though several mentioned the role of exercise (walking, gym) and working. Comments included:

“Work- the structure of it- the fact that I enjoy it and the social aspect of it. The people there that I like.”

“The gym. Instead of the drugs, I worked out every day. Working helped- I worked in a pharmacy

IV. Ending Bad Stretch Sooner **(Question 20)**

The survey participants talked about the help or supports they would have needed to end the bad stretch in their lives sooner. Eleven individuals (46%) said that either “nothing” else could have helped (37.5%) or that they couldn’t think of anything (8.5%). A number of these people stated that improvement depended only on their efforts, essentially taking full responsibility for their recovery. Some comments were

Quality of Life Report

“I don’t think so. I needed to get things back together in my life and then establish a support system that helped when I was really able to get help.”

“I don’t know. I don’t think anyone can discipline me; I have to do that myself.”

“Nothing really. Once I recognized I was overwhelmed I got the support and help I needed. It was up to me to recognize how I was feeling and I’ve gotten better at it over the years.”

“Well if I hadn’t stopped taking my meds it probably would have helped because then I would have been able to think more clearly and probably would have faced my feelings sooner, but I think I stopped taking them so I wouldn’t have to face my feelings.”

As for the remainder, there was a fair amount of variety.

Several (5) people said that going into a particular kind of treatment (egs., day treatment, individual therapy, outreach) earlier than they did would have made a difference. As one person noted: *“Maybe if I had been in individual therapy and could work more intensely on my feelings. I tend to push the warning signs off and don’t deal with it. I know if I dealt with it earlier it would be easier, but that’s me.”*

Some others (5) said some sort of peer support and/or *“steady friends”* would have helped. One person noted: *“More peer support, especially from peers functioning at a similar level as me...”*

A few others said that new kinds of programs might have helped, with one focusing on peer support:

“I didn’t know of any place to go. Having a family that would be willing to talk about these issues. Knowing that people have completely recovered from this state using medications and without. There was a real barrier to me talking about it. I didn’t want to be put on medication. Having somewhere to go having a lot of different approaches to wellness, including meds, but not as a focal point...”

“A place in between respite and the hospital.”

A few people mentioned having more money to support care and other basic needs (eg., bills, art class), exercise (eg., Tai Chi, “group physical activity”), help finding housing, talking to family and practical assistance (“getting to appointments, rides, reminders”).

Others expressed dissatisfaction with services or access to them. One such person said that ICM services had been discontinued prematurely. Another felt that his/her psychiatrist was not listening to his/her needs. Another person said that his/her bad period had extended because of a prolonged stay in a psychiatric hospital, which felt it had to monitor the person due to a high “blood count.”

5	<i>Comparative Analysis</i>
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Demographic comparative analysis revealed significant findings related to how people who are commonly hospitalized viewed different aspects of their lives, as detailed below:

A. Three respondents had 9+ hospitalizations in the last year, and they had the following in common:

- they felt “hopeless” during their bad stretch
- getting the right meds helped them get out of the bad stretch
- they didn’t know what additional supports might have got them out of their bad stretch sooner.

Eight people had 3+ hospitalizations over the last year, with most saying they felt “hopeless” during their bad stretch, and a large majority not sure what other supports might have helped them getting out of the bad stretch.

B. Of eight respondents who didn’t think they could have ended a bad stretch sooner or were not sure how to do so, six were hospitalized in the last year, and five (of seven total) were hospitalized in the last month.

C. Of nine respondents who didn’t think they could have prevented a breakdown after a good stretch or were not sure how to do so, only three of the nine were hospitalized in the last year.

In terms of reducing hospitalizations for these Medicaid consumers, key factors are one’s level of hopelessness during a bad stretch and their level of creativity and thoughtfulness about getting pout of a bad stretch. We recommend that further studies look at this frequently hospitalized group in particular to better understand what their needs and review methods of better responding to their needs. CQI could conduct further in-depth interviews of this subgroup; clinicians could pose the relevant questions to clients and some could be offered the opportunity to interview with CQI.

6

Discussion

Several factors related to quality of life emerged from this survey: housing, employment, relationships, internal resources, routine activities, the assistance of services and peer support, and medications. Housing appeared to have the most straightforward role as being a common problem for respondents during bad stretches and a resource during good stretches. The other factors and some of the questions they raise are discussed here.

Work and relationships seemed to offer tremendous rewards as well as high risk in terms of quality of life. Working was highly valued during good stretches, but also led to or contributed to respondents' bad stretches when they did not have the employment support needed. Relationships were described as critical to surviving many bad stretches, but, again, relationships that broke down often sent people reeling into a bad stretch.

The assistance of mental health services was important to respondents getting out of bad stretches and was often identified as something that people wished they had used sooner. Many respondents saw therapy and peer support services in particular as valuable because they offered support that was dependable and non-judgmental.

A sense of efficacy and control came up frequently in descriptions of good stretches and for those who could talk about how they got out of bad stretches. Many described feelings of hope and competence during good stretches. Many respondents said they had the personal attributes of persistence and a willingness to change, and the ability to take action or ask for advocacy support in getting out of bad stretches. Particularly in maintaining good stretches, but throughout the survey, there were many references to the value of structure and consistency in daily life. This cluster of skills and circumstances supporting both stability and creative change seem very relevant to many respondents' quality of life.

Medication was described as a critical factor for ending a bad stretch or beginning a good stretch by a number of respondents. For some, their stories revolved around the success or failure of their medication treatment in reclaiming stable daily lives. Based on the analysis of how people commonly hospitalized saw their lives, increasing people's sense of power over their bad stretch and working more effectively with medication could reduce hospitalizations.

7

Recommendations

MBHP and CQI have pursued this survey based on the following assumptions:

- People with mental illnesses can, indeed, prevent difficulties and improve the quality of their lives.
- The mental health consumer's perspective is a valid indicator of a system's current success and potential role in supporting and promoting this goal.

Our findings demonstrate that there is usually an environmental cause (ie stressor) of a consumer's mental breakdown, not a random event. Consumers who lacked the requisite understanding or motivation to deal with this stress are more likely to have repeated distress and hospitalizations. **Since this was the case regardless of their mental health diagnosis or stage of recovery, the process of recovery requires support and must assume the validity of an individual's subjective experience.** Thus, the quality of life of MassHealth consumers can be improved if the mental health system and its stakeholders are willing to invest in strategies that:

- are preventive
- are empowering
- help consumers clarify their own values and set their own goals
- provide clear and accurate information to consumers
- provide for coordination of acute and rehabilitative services

The following strategies, though not inclusive, are important components to these ideals:

- **Learn about the Wellness Recovery Action Plan (WRAP) as a crisis prevention and wellness tool for individuals and organizations.** Mary Ellen Copeland developed this self-help approach based on her own personal and family experience with recovery from extreme moods and her research in Vermont with 225 stakeholders, including a majority of consumers. Ms. Copeland's work is based on the key concepts of **hope, personal responsibility, education, self-advocacy and support**, some of the same elements that came up in our survey.

In brief, WRAP offers a framework for people to identify regular activities that support their well being and to make plans for managing triggers. It offers a chance to write one's own description of a crisis and directions for how others can be of help. Ideally, it is a non-threatening way for peers to meet to work out these details. For example, a person might have a written strategy for dealing with the upset of a fight with a spouse that would prevent the onset of psychiatric symptoms.

For more details, a "WRAP Train-the-Trainer" program is already underway in Massachusetts, organized by Cheryl Stevens, Director of Consumer Affairs, at DMH's Western Area Office at 1-888-967-6622 or e-mail Cheryl.Stevens@dmh.state.ma.us. For

more information about starting your own WRAP or about more programs introducing it on a system-wide level, see Mary Ellen Copeland's web page: www.maryellencopeland.com. A wide variety of visual, audio and written recovery materials are also available directly and through web links.

("WRAP" represents a broad strategy and is not for every consumer, but it is a concrete, well thought out methodology.)

- **Learn and teach others about the "Stages of Change" and the empowering process of Motivational Interviewing.** Motivation is defined by Miller & Rollnick as "...a *state* of readiness or eagerness to change, which may fluctuate from one time or situation to another. This state is one that can be influenced."

The stages of change describe a cycle prefaced by one's "pre-contemplation" of change, not even considering or recognizing the possibility or need for change, followed by "contemplation" of changing one's behavior by exploring circumstances, options, consequence and values, then "determination" to change one's behavior which allows for "action" and then the "maintenance" of new behavior. "Relapse" can be expected at this point, though a permanent exit from the cycle is hoped for and always a potential goal. Motivational interviewing is a well researched process for how best to support someone's motivation to enter and to move through this cycle. Understanding the process of change and how to support it in your personal and professional relationships in this way may improve:

1. Your own and someone else's relationship with medications and with treatment.
2. Your own and someone else's success with self-help programs.
3. Your own and someone else's creation and maintenance of a more satisfying life-style.

This method of therapy may be particularly valuable for clients who are resistant to engaging in difficult discussions about medications.

- **There should be a stronger and deeper relationship between Medicaid, the Department of Mental Health, Massachusetts Rehabilitation Commission and perhaps other agencies in order to support consumers beyond their acute care needs**

Our report demonstrates that instability in housing and employment causes real potential consumer psychiatric distress. Job coaches, advocates and others that receive funding outside of the Medicaid system help people move ahead in their lives. We strongly advise that MassHealth place resources to help clients secure their long-term needs, possibly requiring a Medicaid waiver that allows for independent skills based training.

- **Advocate for peer education and support that support the MassHealth client's rehabilitation.** Establish Recovery Learning Centers (RLC) as proposed by the Consumer Family Workgroup (attached). The RLC model is based on the research,

wisdom and experience of people in recovery and offers consumer-driven, localized supports. The RLSs would provide members with accurate information about topics of their choice by inviting experts in their fields to present.

Most important to maintaining community tenure are ongoing assistance with housing and employment. The reason these centers are so important is that many MassHealth clients are not DMH clients, and do not have a continuum of care that provides this assistance in a seamless way.

- **Make available therapies that do not rely on linear, organized communication and experience or traditional settings.** Are people with frequent hospitalizations and a trauma history getting the support that is needed? Are therapists and others given the chance to offer what is needed? The expressive arts therapies incorporate meaning making, through drama, movement, visual arts, music and poetry into the treatment process. They have been shown to be an effective way for some people with trauma histories to re-process disabling memories and relieve symptoms without side effects. The expressive arts also offer unique and effective ways to clarify roles, goals and values in group and individual supervision.

Are a variety of physical, body-based and medical supports available? These may include, for example, personal care attendants, chiropractic care, acupuncture and yoga. An array of treatments and ways of communicating can help people clarify where they are at in the stages of change, particularly in the pre-contemplation and contemplation stages. Personal values and goals can be experienced and understood better, though not necessarily revealed, so that moving into the determination and action phases of recovery is possible.

- **CQI should complete development of a survey tool to help consumers and therapists understand where the consumer is on the recovery continuum and develop strategies to work on areas that will help him/her make even more progress.**