

# Appendix 4

the  
**TRANSFORMATION**  
center



Dear DMH,

**We met in Holyoke MA on July 23, 2008 for 2 hours to go over the RFI and respond.** All of us use DMH community-based services and will be impacted by changes in re-procurement. We are all interested and working to furthering our formal education, including some of us who would like to do the CPS training.

The Transformation Center presented the RFI (tools attached) and took the following notes, verbatim, during our discussion. The questions we answered were not exactly the ones you asked, but all are directly related to the proposed changes. The questions we discussed are in *italics*.

Our feedback has been re-ordered and numbered to match your original questions as much as possible for ease of review. Most of us have included our phone numbers here and in the cover sheet. Please feel free to contact any of us directly or through Marcia Webster at The Transformation Center for more ideas or if you have questions.

Sincerely,

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Anonymous

### **A3. Facility-based Respite**

*If you needed “respite”, would you rather go to a place with staff there all the time OR have providers to come to your home?*

Depends – 1

I would stay at home ONLY if I could get added supports. Otherwise, I’d go to respite. It can be more aggravating with other people there.

Respite programs should be there, but people also need their privacy.

Staying home it better if your therapist, someone who helps you stay stable, could come to your house and give you services once in a while - or on a regular basis.

Would want to get away – 3

If people come to your house to provide services, you could get worse in your own place after they leave. Things wouldn’t change enough and you’d be alone again.

In the past, it’s been true that a change of scenery did help.

### **B1. Strength-Based and Person Centered.**

*Does staff turnover change how well or how often you speak up for yourself?*

No – 3

As long as there is someone there who can give you time to understand the paperwork or main concerns, in a kind way. Someone who has been there for a while, a supervisor or assistant is who I'd go to with issues.

## **B2. Risk Management**

*Are Rogers Orders (forced medication) or Representative Payees (someone else uses your money to pay for your basic needs) ever necessary or helpful?*

Yes - 4

But you should never be forced to take medication just by itself, ever. It is not the most important thing. Skills are just as important. In my experience, you have to train your mind to not be on medication so that you can help yourself.

IF someone is forced to take medication, it should go along with skills training and treatment. I requested Rep Payee once and it helped. But it's been a downfall because staff are not aware enough of SS benefits. SS won't give you info if you are not own payee. I've been underpaid more than \$100/month when moved to another residential program and staff let it happen, I had to go down. Education of staff is essential, participation of person who knows the SS system.

I wouldn't be on meds w/out Rogers and I'm doing so well. So it's helpful, I'd be doing worse. Rep Payee can be helpful. Depends a lot on Rep Payee, how much they want to save. But should be able to get what you need.

I've had staff forge my signature on paperwork for SS.

## **B4. Peer and Family Support and C5. Utilization Management**

*When you are well and not well... How often do you need to talk with a "peer" (someone who might be helpful because they've also been through something similar)?*

I would like a Peer Specialist as a mentor – to talk with and to get advice from someone who's gone through it. I'd like the PS to talk with me, come to my house, go out and do activities... I get anxiety on the bus or going out. Someone to check in with every day, have a conversation. We could work on skills and techniques they know and I could use.

I have a Peer Specialist, I go to their groups. It's more open and I hear recovery experiences. I talk to the Peer Specialist everyday – they are very understanding, they can help with anything – being a friend, solving problems. As a friend, I know the PS has time for me at the program, when it's possible.

I'd meet with a peer worker twice a week when well. When I'm not well, they could help, but not as often because I don't like to talk to people then. When I was hospitalized, I wouldn't talk to anybody, not peers. Once I was back on meds, I came around and talked with people.

## **B8. Standards**

*Re: Word Frequency chart*

“Symptom” is not an accurate or useful word, it’s not a good way to describe us.

## **C4. Incentives**

There should be more funding, enough to actually cover the cost for transportation services.

Staff are not getting enough mileage, they are coming up short, losing money, and people aren’t going out as much.

## **C5. Utilization Management**

*When you are well and not well... How often do you need to talk with a “mental health clinician” (someone who might be helpful because they’ve studied the topic and made it their profession)?*

When I’m not well, I need to see a clinician more.

I need to see a clinician as much as possible when I’m not well – at least twice a week.

I need to see a therapist and psychiatrist regularly all the time

## **E3. Assessment/Treatment Planning**

*Would you like to write your own program goals and notes?*

Yes – 1

If I had input and the option to add comments, that would be good – 2

*Is it useful for you to document (think about, write down, draw, share with others...) the steps, strengths and challenges of your recovery/life?*

Yes – 2

I make worksheets, a diary card, with different questions and keep track of different symptoms, identify what helps on what day. In deep depression it’s hard to remember, so if I write it down and it shows me what helps and doesn’t.

It’s good to have other’s input too, they see something I might not recognize or remember saying or doing.

*Is it useful when a staff documents your recovery/life?*

Yes – 3

As long as there is input and the option to add comments.

It’s helpful to have them document what they see, what you say. But you should be able to write your own goals and not force people to do things, get a job, when they’re not ready.

At one time it was helpful to have staff write notes, at the sober house, because at the time I needed to be monitored. I don’t have that need now.

*(MHSACM update handed out)*

*Would it help if all the programs used the same forms to write about your progress?*

Yes – 2

If it all looked the same, had the same headlines, so staff could look at notes in each facility and see how you are doing on your planning somewhere else.

Down-side – Sometimes you are in different settings, so the forms should vary from program to program as needed. Some would be the same though, like the goal sheet.

Standardized electronic records could be good, but...

People should NOT be able to rewrite what others have written.

People who should not have access shouldn't be able to see or change your records.

There is the possibility of invasion of privacy. You can already go online and pay a fee to get anybody's records; their CORI or credit rating.

## **F2. Housing**

*It seems that DMH wants to provide as much or as little staff time and assistance to people living on their own so that group homes can be closed. Do you think this is a good plan?*

It's a good idea overall, but...

It depends on the person. Some can't be alone. We need some group homes.

They should be rearranged to be transitional, short term only. There has to be some sort of service and place for transition, esp. from the hospital; a place where people can be together.

Living in a group home can set people back if it's not the right setting. Or people get too attached. Some programs don't have chores so people aren't learning skills to transition to their own place, like taking care of the trash going out, knowing about things like that.

Don't cut out ALL the group homes, but put a lot more funding into people to help them live independently – alone or with roommates.

It is possible that long-term respite could turn into a group home.

*Do you think DMH should separate money for housing (shelter, utilities) from money for staff and rehabilitation services?*

It's hard to know - 2

Yes – 2,

Providers should keep their money for housing separate.

But DON'T cut the funding! It might be easier to cut the budget if monies were kept separately.

## Peer Group 7-25-08: Feedback to DMH about the RFI

The following dialogue was recorded at a meeting with five people who use mental health services. It was typed into an overhead projector where all participants could read and review it. All wish to remain anonymous. Marcia Webster will contact participants if DMH has any further questions or feedback for the group.

The meeting was scheduled in order to write a respond to the RFI. It began with a reading of Commissioner Barbara Leadholm's letter introducing the RFI. The group went over a one page summary of the RFI prepared by the Transformation Center (attached).

The dialogue that followed is recorded below. As you will see, comments do not respond to specific questions posed by DMH. Formatting and themes have been added to assist readers in tracking topics and comments.

In regards to the RFI and planning this meeting, people in the group said that it is difficult to stay informed and involved because communication and information is often shared only on-line. Not everybody, or even most people using services, have access to a computer!

### Respite

*Most of the time I have to be around lots of people, but sometimes I have to be alone, absolutely without anyone around. I would like to have respite come to my house – a crutch for a few hours, I could tell them how I feel.*

*The respite and ER system is not practical, I don't need it during 8:00-5:00 work days. It's 2:00-4:00 am or 10:00 pm at night that I need to talk to someone, when people in the building are too loud.*

*At 4:00 pm I always think, Ok, they are not available now, I need to shut down because they are assuming I'm safe until the next day. Time to fake it until the morning when I can feel again. Even calling respite doesn't allow me to feel at ease.*

### Clinicians and Training Needs

*There should be a re-education of doctors who were trained 30 years ago. People who are new in the field may be saying, "this is how it works, we don't do it that way any more." But old school staff says, "No, we don't believe that."*

*If all the social workers and professions agreed to try something new, than the doctors would have to agree. DMH should start a pilot program.*

*I don't think physicians take mental illness seriously, they just want to give pills. But we need to be re-trained about how to think, act and cope with life. Doctors don't give that information, or are reluctant to think about it.*

*The doctor and psychiatrists will write a couple things about how you feel, give you a couple pills, have a good day. There are other people who deal with that coping with daily life. Some people don't have those other services. I've had multiple help, but others haven't.*

*I had a medical doctor that I loved. I'd walk in, he'd look at me, ask how I was. He went away. The next doctor wouldn't look up, sat hunched over his papers, no eye contact. I was there for 8 minutes and left with a script.*

*It would help to get continual feedback from people about what doctors really make a difference, doctors that check my progress. It's all about helping me move toward wellness. The second doctor was placating, keeping things a bay, I never got the sense he cared.*

#### Re-traumatization & Disregard

*I hear that, the doctor is compounding the problem by ignoring you. Yes, The first doctor would ask about all kinds of things, like my art. He saw me as a valuable member of society.*

*I agree, I've heard about doctors that were ambivalent, they just gave a pill, they didn't want to get involved in your emotional problems.*

*Clinicians need to be trained in trauma sensitivity and disease sensitivity. At an annual goal meeting, staff turned their noses up at my bringing information about bipolar disorder.*

*I have illnesses I have to go to bed for a few times a week. There was absolutely no allowance for this. It was an overwhelming feeling to get from outreach workers that I was LAZY. They called me a name and made jokes at my expense.*

*I've been cut into ribbons by outreach workers, they have been very disrespectful. I talked to one of the DMH workers a number of times and they nod and smile... and nothing.*

*I'm treated by DMH workers as though I'm the problem. I've been yelled at by DMH workers and I cried, almost had a breakdown. They yelled at me. They are paid, I'm a client with mental health issues.*

*I have to take time to prep for seeing my worker and it takes time to recover from it.*

#### Stigma & Disrespect

*The public doesn't understand or take us seriously. We're seen as lepers, like we can't function. So people won't give us a chance to be real, helpful, kind...it hurts. Even it doesn't show, it hurts inside. People don't understand that you were whole at one time, but something happened to you. It's like a cancer, it has to be dealt with.*

*I got a new worker and I was panelized for showing that I was upset. They wrote me off for a month. Nobody had asked me what happened. So I stopped trying to defend myself, what's the point?*

*It bothers me when staff ask, "Are you SURE????", asking it over and over and over when I've decided to do something. Staff thinking that I couldn't handle it.*

*I see staff picking and choosing who they want to spend time with. They hurry to meet with someone else when they came late to see you to begin with.*

*Every time, I've tried my best to know about myself, I'm willing to stretch. I let workers know how far I can stretch myself, but I find that when I go to meetings it feels like I'm asked to not be mentally ill. It's hard to talk even here.*

### Complaints Process

*There are channels for where to go with complaints. But it's like climbing a rocky cliff. They ask, "Are you sure that's what happened? Are you sure you didn't do..." Months and months go by and you don't hear anything.*

*Then, they refer you to someone else. If you get to the top, people are still insensitive and walk all over you.*

### The "Difficult Client"

*Your name is out there, you feel like a target if you complain. Why can't we be anonymous when we make a complaint? Staff knew I complained and I was treated so differently, you're defiantly targeted. But their names aren't out there and they are work for US! We are consumers; we are paying for the services.*

*When people have a "get over it" attitude, it's very disaffirming and makes me feel like a loser. It's shaming. When I have to hide my pain from my worker, I feel paralyzed and can't say or ask for anything. So, I become a "difficult client".*

*They make you feel like complaints come at a bad time for the complaints division. Or, the complaint someone makes becomes a judgment about the individual who complained. But its OK occasionally for staff to need it "easy", so I don't always share my difficult feelings or problems.*

### Advocacy

*It took 6 months for my complaint to go through. I had nobody, I had to do something, it's a constant fight to wake up every morning and go through that again. I have to scratch my way out of the pit. I was fighting for others that helped, too. Others that need hope, that need a leader to stand up and give voice.*

*It's hard to even show up, like today. But if we do, its' a chance to get more grants. It's so sad that I can't ask for a new worker without changing and straining the relationship. I don't know how to bridge the fact that s/he feels bad because I want a new worker.*

### Sensitivity Training

*This "get over it" attitude is common among DMH workers and the top guns of agencies, the people you have to go to. Clinicians, case managers, outreach workers ALL need to learn about recovery, be trained to be sensitive. They need to learn paths to recovery and acknowledge that I'm fragile.*

*I felt better when someone, a therapist, said the truth, that the suffering I go through is inhumane, "It is terrible that there are no supports when you need them. I respect your decision to handle it however you can."*

*When you treat people with problems, and mental illness is a hard one problem, an invisible disease, and you treat them with less dignity than God gave them, you are treating God that way. God is in everybody's soul. You are culpable for what you do when you treat people without dignity.*

### Peer Workers

*We can applaud DMH for funding peer workers. But people who have peer workers are not always aware that they can come to people's home.*

*I love the idea of peer workers in all programs. DMH has to address the level of condescension from other workers and the stigma that happens because that peer is a person that receives services or has had trauma.*