

Central NY Field Office
Regional Advisory Committee Input
April 1, 2013

1. What do you like about the managed care approach presented?
 - a. Reinvestment in peer services
 - b. Big picture holistic approach
 - c. Effective communication to understand it better
 - d. More control of options
 - e. More choice
 - f. Person centered
 - g. More peer oriented than current service models
 - h. Slower explanation of services and how the process works
 - i. More effective transition services, having any transition process at all (“they say this happens and it does not, we still get dropped like hot potato”)
 - j. Shifting more towards peer support inclusion
 - k. Forensics connections and trauma informed approach

2. What do you not like about the managed care approach presented?
 - a. We need more training on the overall changes coming, hard to understand since no one taught us the current model and how it’s funded
 - b. Spend more time on training for this idea
 - c. Share info in advance so people have time to research
 - d. Possible co-pays not currently in place and unnecessary burden on limited incomes
 - e. Unsure of how the monitoring and auditing process will be applied and who will be taking feedback from recipients and families on the issues with the new model

- f. Reinvestment savings not going to tax payer relief
- g. Deterioration of quality of care
- h. Lack of person centered choice
- i. Lack of flexibility in choosing service providers
- j. Not enough service options on the menu
- k. Access to services diminishing
- l. The “high functioning” being kicked out of services, we are high functioning because we receive services – take them away and we are no longer high functioning
- m. more decrease in time spent with therapists and psychiatrists (“last visit to my psych doc was 7 minutes which is not appropriate for proper medication and side effects discussion”)
- n. More forced treatment
- o. Lack of real recovery options beyond the medical model
- p. More medical model cycle of un-recovery
- q. Confidentiality breeches, sharing of info without consent is happening all too frequently with Request Of Information as it is
- r. Lack of access to nutritional wellness that is currently available in many programs, lunches that are nutritional (I will lose one meal a day without these services)
- s. Human rights impact is not clear
- t. Not moving away from micro managing people’s lives and still a cookie cutter approach, we need adult to adult relationships with providers (not glorified babysitters)
- u. No information on how the aging or child populations are considered under these plans

- v. What about people on Medicare who do not have Medicaid either from not qualifying or personal choice not to pay spend down due to living expenses?
3. What service(s) do you think are needed in the Health And Recovery Plan, (HARP)?
- a. Should be available to all types of insurance or payment
 - b. Peer run respite services
 - c. Peer run clinics
 - d. Peer clinicians
 - e. Embrace choice not to utilize medication as a recovery too
 - f. Utilize a Soteria House model of recovery
 - g. Access to spiritual enrichment resources
 - h. Acceptance of alternative tools of recovery
 - i. Utilize SAMSHA's 8 dimensions of wellness
<http://store.samhsa.gov/product/SAMHSA-s-Wellness-Initiative-Eight-Dimensions-of-Wellness/SMA12-4568>
 - j. Person centered (the real version where my choice is accepted and not coercion to down grade my hopes and dreams)
 - k. Must have a real informed decision making process
 - l. Ensure workforce operates with an adult to adult approach, not the parent to child non sense we are expected to swallow
 - m. Nutrition and wellness
 - n. Must have options for second opinions when a recipient disagrees with a clinicians diagnosis and treatment, we have been misdiagnosed before
 - o. More networking to meet a person's recovery goals and deal with issues through more effective networking within the community (should include natural community supports not just typical mental health systems supports)and should always be real person centered options

- p. Options for veterans
 - q. Take a more serious approach to trauma informed care, one man's bump in the road is another man's mountain
 - r. Support for parents such as respite options for much needed mental health breaks, etc. (could be in the form of access to a few hours of day care for children or sitters available to prevent relapse issues)
 - s. More alternative services such as Reiki, chiropractics, yoga, meditation classes, etc.
 - t. Fund alternatives
 - u. Access to education services
 - v. Support creation of peer run businesses
 - w. Money to attend conferences and other training/classes to expand recovery knowledge, should include alternatives conferences
4. What are the concerns and or benefits about expanding peer services under managed care?
- a. Benefits
 - i. More money from re-investment
 - ii. Peer services for relating in a mutual support process
 - iii. Increase in peer staff numbers
 - iv. Helps informed decision making
 - v. Being creative in problem solving
 - b. Concerns
 - i. Less autonomy of peer services'
 - ii. Lack of flexibility in care plans
 - iii. Not utilizing peers with personal experience of having moved through the system of care, college degrees do not mean jack when there is zero real

lived experience (you have peers in charge of services who have no clue what it's like to live homeless or beg for food)

- iv. Having any accreditation process or definition of who a peer is
- v. Too high of a standard in accreditation process
- vi. Forcing unprepared and unwilling staff to change at programs ensures the lack of decent care to people they serve (example: PROS conversion was a horrible experience without the real feedback of peers)
- vii. Possible co-opting of peer services to collect peanuts while selling out the peers to meet their own needs (actually already happening on a wide basis)
- viii. County control over peer services will increase instead of diminish

5. If you had a magic wand what would you do to make managed care work for people with mental health needs?

- a. More monitoring of behavioral health services, must have on the spot inspections where agencies do not know you are coming
- b. Stop putting us in boxes and listen to the plan we have for our own lives
- c. Take a serious look at the legal system and how it just assumes too much about what we might be capable of and train the judiciary extensively on recovery, the current system actually takes advantage of the labels placed on us and not the actual functioning we are capable of
- d. More support for legal processes so we don't end up with a prison record to boot on top of a mental health label
- e. Throw out the Diagnostic and Statistical Manual 5
- f. PLEASE INCREASE THE Supplemental Security Income/Social Security Disability Insurance AMOUNTS, WE ARE NO LONGER LIVING BUT

SURVIVING (MY FRIEND SUICIDE NOTE STATED NOT ENOUGH MONEY TO LIVE ON ANYMORE WAS REASON HE OVERDOSED HIMSELF)

- g. Partner with companies like Tide, (detergent) to create programs for people to afford the upkeep of clothing and bedding (would go a long ways to ridding the epidemic of bed bugs statewide), like they did for the hurricanes

http://www.tide.com/en-US/loads-of-hope/index.jspx?utm_source=google&utm_medium=cpc&utm_term=tide%20loads%20of%20hope&utm_campaign=Tide_Search_Desktop_Brand+Advocacy&utm_content=sJ78FAxtu_16715145316_e_tide%20loads%20of%20hope

- h. We must have more therapists trained in Eye Movement Desensitization and Reprocessing, (EMDR) and other more expensive training modalities as we lack these qualified people, agencies should be willing to pay the higher upfront cost to be more effective in diagnostics and treatment