

Central NY Field Office

Regional Advisory Committee Input

August 27, 2012

Also includes points from CNY Voices Onondaga Chapter Pre-RAC meeting on 8/7/12

In what areas should we be working on?

- Staff Competency and Support – Measure the competencies of staff by evaluating if they have the training required and are regularly getting the training updates they should; Make trainings in cultural competency, peer and family support required training for all staff; Develop a training for staff that supports informed choice, including support for those who choose alternatives to psychiatric medications; Develop a peer educator/navigator position that would have a dual role of assisting programs, schools, etc. by educating them in peer support/person centered planning as well as educating groups of peers on how to navigate effectively in the community; Ensure that staff are regularly trained in vicarious trauma as they also see much that can impact them as human beings; Review the wages of the workforce to ensure that we are attracting quality staff, \$8/hr does not attract quality aides, mentors, etc.
- Trauma Informed Care – Peers recognize region wide that trauma is being very narrowly defined by many systems providers and ask the following: Provide trauma informed care throughout the system, recognize that trauma can be caused by anything a peer feels traumatized by, not just the typical areas people focus on as trauma, providers should be speaking to people about trauma as many peers have either been traumatized or supported one who has; Recognize that better after care post-ventions need to be developed to support peers and families in programs after a recipient has died in the program (one meeting of a community residence after a death is not enough support), some peers have literally watched many people die in various programs.
- Advocacy Supports – Develop a mediation method for disputes between those served and treating clinicians; Ensure that there is at least one advocacy support program in each county that can actually assist and support a peer/family member in obtaining services through attending meetings with people (all too often even the most effective advocate needs another support as they become drawn into the emotional dynamic of the advocacy);
- Physical, Emotional, and Spiritual Supports – Develop more transition supports between levels of care (warm hand offs, not dumped waiting for the next service level); Better education to peers and families on the Health Home changes and how it affects their rights; Develop peer navigators/mentors positions that can

assist peers while in transition, employment, school, life, etc.; Mandate that staff actually spend more time with individuals during appointments, 15 minutes is hardly enough time to have a proper medication discussion in the fully informed consent approach; Assist individuals into tapping into talents first before pinpointing the negatives; Providers must respect our choice of spirituality instead of diagnosing us as mentally ill, one man's perception of a delusion is another man's connection to spirit; Establish totally peer run community residences that would function less clinically and more practically in assisting people to get back to life, could be a step between Community Residences and fully independent housing; Revisit Family Home Care as an option again with better guidance; Create community navigators to assist peers in engaging beyond the mental health system; More funding for Recovery Centers; Create life coaches who are cross trained in physical disability issues as well as mental health as many of us end up with serious chronic medical conditions due to medications; Improve the quality of service coordination upon release from in-patient units and criminal justice settings through the use of peer specialists/peer bridgers; Knowledge of resources remains a major barrier to peers and families in every community, require every county to publish and make available copies of all services across the board including doctor/dentist lists and the insurances accepted; Ensure that all programs are allowing peers to access resources via the internet and other means; Providers must go beyond minimum assistance and help us strive to attain our own goals not theirs; Medication education is something that should be mandatory when prescribing any new drug to a patient so that effective communication occurs between the patient and other providers, include all the facts of the medication not just the benefits; Many peers and families are dealing with the need for physical health care through home health aides, etc – communicate with the Department of Health that peers can and do make sound decisions for themselves and that planning for these services should be based on patient needs and not home health aides/agencies needs; Youth transition training must start in school as schools are failing our children in being prepared for the basics of life, suggest a look at youth mentoring programs in other countries as well as in the USA; Take a look at the foster grandparent program of Peace, Inc. in Syracuse NY as a family style support for adult peers, especially those who have no families (would be less restrictive than a family care home setting); Don't kick us out of therapy when we take an alternative to medication approach because the agency mandates you must be seeing a psychiatrist to see a therapist

- Housing – Don't shut us out of housing (or other) supports because we choose a non-medication approach to recovery, we still need supports; Stop building/locating housing in unsafe and violent neighborhoods, we deserve better; Create housing programs that assist peers in obtaining their own homes; Rehab existing vacant buildings in cities to create housing and affirmative businesses co-located; Create community living settings without identifying them

as places of the mentally ill so people can naturally blend into the community as a regular part of it instead of labeling them with stigma; Eliminate the usage of bad credit scores in all housing as a discriminatory practice, peers end up with the worst places to live because they live on little to nothing often being gouged for every dime a landlord can squeeze leaving them with no money for essentials such as grooming, household expenses, etc.; Support public non-profit housing organizations in being able to accept corporate donations for things such as household supplies, furniture etc; Utilize any and all green initiatives in the building and rehabilitation of housing stock; Assist peers and families who are struggling to stay in the homes they own with better tax breaks; Create better preventative measures to ensure peers do not become homeless, don't require someone to be homeless to get services as it hurts families who have to kick their adult children out on the street for them to get adult services; Waiting lists for housing and housing support are far too long;

- Financial Support – Benefits planning training must be an ongoing thing, each county should have a minimum of two trainers who are available to assist peers and families and train the workforce, peers and families; More support for peer run businesses such as how to write a business plan, etc; Increase in state supplement to SSI/SSDI to cover the rapidly rising cost of living as in reality the federal adjustment has never aligned with the real cost of living; New York State should advocate for a federal increase in SSI/SSDI rates or other avenues to stretch the benefit further as we are barely surviving let alone living; Bring back stipends and vouchers for assisting programs as it is an effective way to draw some towards seeking employment; Credit reports should not be allowed to be used when obtaining housing or employment; Create better transportation navigation training statewide to assist peers in utilizing transportation;
- Education/Employment – Educate PROS programs and other employment support programs that it is our right to develop a business model that we choose, such as being told that Reiki is not a viable business format because that program/provider does not believe in this alternative format; Make all employment programs available to those who do not choose psychiatric medications; Ensure that youth are being provided pathways to higher education by schools who have a not so healthy track record of supporting students with disabilities; Continue to work with State Education Department in developing supports for transition age youth who are falling through the cracks; Require Functional Behavioral Assessments and Behavioral Intervention Plans be aligned to the federally suggested format which is a comprehensive formula that works in determining a child's triggers and ways to help them to learn to overcome them, currently there is no mandated standard; Ensure that staff being hired for special education classrooms have the appropriate credentials; Ban the practice of denying one on one aides based on the economic struggles of schools; Ensure that children in foster care have a permanent independent living plan which includes higher education planning and technical skills development;

