



**Final Report:**

**A Day in the Life Project (ADITL Project)**

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## NCRMHB REPORT ON PHASE TWO FINDINGS FROM ADITL PROJECT

**Background:** Phase One: Initial analysis and findings: “A Day in the Life” initiative was designed to enlighten the providers of the behavioral health system and the general public about the daily lives of individuals receiving services from the Connecticut Department of Mental health and Addiction Services (DMHAS). Eighty people who receive DMHAS-funded services participated in the project. From their own perspectives, these individuals talked about their experiences, beliefs and perceptions of DMHAS services they were receiving as well as the successes and challenges of their daily lives as people living with mental illness, substance abuse disorders and co-occurring disorders in Connecticut in the early Twenty-first Century. Their stories are important, as illuminated in the initial analysis of the first 25 of participants’ experiences and their beliefs. Findings of the initial phase were presented earlier and have:

- illuminated the hardships and challenges of mental health and substance use concerns;
- illustrated the achievements and talents, dreams and disappointments, the humanness and hopes of participants;
- identified many culturally accepted, prejudicial notions about mental illness that contribute to the systematic social exclusion of people with mental illness and substance use concerns.

The project team’s report on Phase One is available on the website of the North Central Regional Mental Health Board (NCRMHB; [www.ncrmhb.org](http://www.ncrmhb.org)).

Phase Two: Report on the analysis and findings of the final phase of the project: With the generous funding of DMHAS, NCRMHB renewed its work on this project in December 2011 and completed the project in June 2012. Project researchers have conducted thematic analysis of the remaining 55 interviews and have developed findings from the analysis. An extensive list of themes emerged from Phase Two analysis. Reported here are findings from four selected themes: hardships; challenges; hope for the future; and reclaiming life.

NCRMHB and project team members hope the project findings help to eradicate prejudice and discrimination and dispel myths about individuals with mental illness and substance use concerns. The report attempts to convey new understandings that can potentially spur improvements in the present-day behavioral health services system in Connecticut and can also potentially promote positive change in the lives of state residents.

## **Introduction to Phase Two Report:**

### **Bike riding as a metaphor for recovery: Getting on, falling off, getting back up again.**

During a recovery-oriented conference held in Hong Kong in 2010, the image of riding a bike was conceived as a metaphor for the recovery journey. This report employs the same image as a metaphor for participants' recovery from mental illness, substance abuse or co-occurring disorders.

One participant's vivid recollection of learning to ride a bike is used to introduce the metaphor:

How could I forget my mother? She's helped me with learning how to ride a bike. ... How I'd run into stuff and fall and she had me get back on the bike and try again. ... [I] had to get back on that bike!

As in the example of learning to ride a bike, recovering from illness is not linear process; many attempts are made as the individual acquires the skills and develops the necessary knowledge, confidence to journey in recovery with mental illnesses or disorders. As with riding a bike, each individual experiences the recovery journey from her or his unique perspective. Like biking, journeying in recovery commonly requires each individual to draw upon core strengths, resilience, and courage. Accumulated wisdom arises over time and capabilities increase, strengthening the ability to navigate through familiar and unexpected hardships and challenges of daily life with illness or disorder. Off the main path are offshoots that require making decisions, to stay the course or make a change and transition to a new path. When a particular path yields little satisfaction, turning points may occur, with turning back and starting again with new sense of direction. The path may present potholes, curves and rotaries. Needs may arise for new resources or new skills or the application of existing skills or the supports of others as guides. Immeasurably beneficial are experiences of positive support from trusted others. Like biking, the journey of recovery gives rise to new sets of skills, increased self-knowledge and awareness, and resources and supports that help promote well-being. With bike-riding a metaphor for the recovery journey, the findings are presented in the next section which have emerged from the analysis conducted by the ADITL team.

### **Selected Themes emergent from Phase Two Analysis:**

#### **Significant past losses and anticipated future losses and concerns about survival.**

Participants with mental illness, co-occurring disorder and substance abuse often expressed concerns about being able to survive in the future. Concerns about future survival were often embedded in experiences of past loss or worries about present-day and future experiences of loss. Differing perspectives arose about the ability to survive in the future with an illness. One perspective was provided by a group of participants who perceived the world as a hostile place in which events occurred at random and with unpredictability. Among this portion of project participants were individuals who reported that their childhood experiences had exposed them to violence, abuse, neglect and other trauma. The consequences of their experiences of the loss of safety and security in childhood were illuminated in their beliefs and perceptions about the ability to survive in the future.

The loss or absence of a safety and security in the early developmental trajectory is contrary to the cultural expectations of childhood experiences. Normative developmental trajectories are presumed to provide the child with a foundation for autonomy, independence and healthy attachment bonds in adulthood. In exploring the beliefs and perceptions of the subset of participants who experienced the loss of childhood, their views were found to resonate in part with widely held cultural beliefs and values: These participants highly valued personal autonomy and independence. Moreover, having perceived themselves alone in an unfriendly and unsafe world, this subset of participants described feeling independently responsible for their own survival. Surviving alone with illness or disorder in a hostile world was perceived as an enormously difficult, daily challenge, as illustrated by a participant who described himself as ‘54 years old and still dry’:

I never thought I'd see 50. ... Life is tougher than you think. It is difficult. Survival is very difficult. I wouldn't have believed it. I'd have called you a liar. You have no choice. Life is tough. You just have to keep on going and hope for the best.

Fear of becoming homeless was often cited as the greatest concern about the future from the perspectives of the group of participants who felt solely responsible and alone in a dangerous world:

Worrying about shelter, apartments. If I'm out on the street, I am kind of scared of that. ... I was going to a shelter because I didn't have references to get into an apartment or anything. Proper references.

When describing what would make the future better, one participant responded that his highest priority was to assemble the resources necessary to survive homelessness independently, since he perceived that in the event of becoming homeless, he would lack the assistance of caring others:

Getting a car and registering the car. Someone told me one time a car is like a house that gets you around. ... You can sleep in it.

In contrast to perspectives toward the future survival that were shaped by a loss of safety and security in childhood, other participants talked about survival in the future and linked their concerns to experiences of past, present-day or anticipated future losses. In their concerns about future survival, two types of loss were identified: (1) diminished physical and biological functional capacity and (2) interpersonal loss, such as diminished connectedness or the complete absence of important sources of support.

Biological or physical losses were attributed to one or a combination of three factors: medication side effects; effects of heavy and prolonged substance use; and the natural processes of aging. Biological losses were experienced in diminished energy, motivation, physical health and stamina. Interpersonal losses were described variously as a complete absence of important relationships that have included family members, friends or employer-employee relationships; or relationships sustained by only limited contact with little emotional warmth and connectedness. A loss in one domain, whether biological or interpersonal, often reverberated in even more losses in

other domains of daily life. For example, in a recollection of being forced out of his family's home, a participant's account illustrated the multiplying losses following the first one, which was the interpersonal loss of family connectedness.

I had a job offered me at [a local company]. I wanted the job badly. As soon as I got the job, my parents threw me out of the house. I was on the road living in my car. I couldn't shave in the morning. I couldn't shower. I ended up losing the job.

Participants concerned about the future included those who anticipated the death of a parent or loved one. The most often mentioned anticipated loss was the death of one or both parents. Several participants expressed discomfort and uncertainty about the changes that would ensue following the death of parents with whom they shared residence, food and living expenses, and household maintenance, as illustrated below:

My parents are getting old and I think they are not going to live much longer, so I am thinking about how I am going to support myself. I am thinking of living in the same house where my parents live. That is where I live now. I live with my parents, and I am thinking of living there after they die and just the extra burdens of maintaining the house and dealing with all the challenges and problems of life by myself in a house.

Some participants described their parents as having been primary caregivers since the participants' onset of mental illnesses. One participant had developed feelings of lifelong dread and doubted the ability to be resilient under the circumstances of her mother's death:

In regards to my own death, I want to die before my mom. I had wanted to die before my dad. I've always wanted to die before my parents. Because I didn't think I'd be able to handle their deaths. I've been preoccupied with that since I was a kid.

Many participants lived with their parents on a daily basis and benefited from the present-day financial security their parents had achieved. One of these participants contemplated optimistically the possibility of receiving a future inheritance from his family's wealth that would potentially help to alleviate his continual worry about survival and financial security:

It keeps coming back to money, but that's the way it is. If my father come up with some money for me. My father is 80 and my mother is 70. If one of them would pass on, I don't know if they would leave me any big money. If they did, that would help a lot.

Although optimism was expressed about potential inheritance, this participant and many others seemed to lack information about the legal and financial procedures governing inheritance processes, an important concern for families who seek to protect and pass down the family's accumulated wealth following the death of the parents. Estate planning and wealth management were particularly significant areas of concern from the perspective of participants who occupied two roles: that of adult member of families with considerable inheritable wealth and that of adult child who has a disability for which state and federal assistance was provided. Below is one participant's account of the dilemma faced by participants who have occupied both these roles:

Four years ago, I had \$7,000.00. The State took \$5,000.00. My grandma passed away. She left me \$9,000.00, but the State took it. I couldn't believe that they could take that much

Illustrated in the example was a consequence of being a surviving member of a family that had accumulated wealth who may have done inadequate advanced planning or lacked knowledge about the laws governing inheritance. From the participant's perspective as a member of the next generation of the family and also an individual who received monetary support due to disability, his inherited share of the family wealth had not been protected sufficiently.

When participants needed services, resources and treatment, participants' help-seeking acts were expressed by individuals whose perspectives were shaped by various concerns about the future and a range of experiences of loss or anticipated loss. Upon receiving services of the CT Department of Mental Health and Addiction Services (DMHAS), participants had core strengths and self-identified needs and encountered various difficulties, challenges and successes in getting their self-identified needs addressed. Under the next subheading, examples from participants'

accounts are provided in which they describe their interactions with the system, both at a system-level and at the interpersonal level with individual staff members as representatives of the system.

**The silencing of participants' voices within the system.** Participants described interactions with the DMHAS system in which their voices were silenced in various ways. During interviews, participants described their needs from their own perspectives and they recalled the different interpretations of participants' needs as developed by staff members. Below is a participant's recollection of the guidance obtained from his vocational provider's guidance:

Since I live with my family, I need not to worry about that right now. At least I could just stick with the [social club] and career opportunities and I will be set for a while ... and if I am ready enough, if I am prepared, I can probably get some housing. I want to get in the housing program here but maybe I can also ask for - like - independent housing or something like that.

As a young adult, the participant did not separate his need for work from his global developmental need to achieve autonomy from his parents. From a cultural perspective, attaining autonomy from family during young adulthood is considered a developmentally-appropriate and highly valued goal. The participant attempted to voice his own priorities, to establish independent housing, an act that symbolized the young adult's autonomy from parents, his the global goal. His voice, however, was silenced. In the participant's recollection, service providers viewed his needs from a constrained disciplinary perspective, thus guiding him to prioritize vocational and psychosocial rehabilitation; furthermore, service providers guided him to defer his housing concerns until a later indeterminate time when he would be referred to another department specializing in the housing area.

As in the above example of the young adult, participants' developmental and holistic perspectives were silenced through the segmentation of services according to the professional's disciplinary perspective. In experiencing the silencing of their voices, participants were disempowered from defining their own needs as service recipients. Consequently, the participants

experienced services that were oriented to and constrained by the disciplinary perspective of the provider's profession and expertise.

**Ignoring participants' voices and core strengths.** Participants had many core strengths. For example, many participants had attained high levels of education, including degrees in electrical engineering, physics, philosophy, and graphic design. Some participants perceived that their mental health counselors and vocational rehabilitation were dismissive of their core strengths and thus undermined participants' goals to build upon their core strengths. Illustrating this point is one participant's account of her interactions with the Bureau of Rehabilitation Services:

I was able to win a full scholarship for my last ... community college ... course. It was through EPS Printing that I got the scholarship. So now, I have started back working with the Bureau of Rehab Services, but I find that for a person – I am not saying this to be condescending – the BRS person even said that: She finds people unskilled jobs, so when person comes to her with a skill, they don't know how to help me out. ... I wanted to apply for a job as an illustrator of children's books. ... She was rude and insulting to me.

Although in the above example the participant openly expressed dissatisfaction with the service provider's attitude toward her core strengths, other participants seemed reluctant to acknowledge that the difficulties they experienced with their providers. For example, a participant began with an optimistic account of having earned a certificate in phlebotomy and EKG and then being linked to the Bureau of Rehabilitation Services:

I get a lot of support [from BRS] ... and the person they have working with me. I am very anxious to work. My days are long now. I took a course in phlebotomy and EKG and I graduated in January. Ever since then I have been looking for work ...

Emphasizing the positive, she described how others were 'supporting' and 'helping' her through the job search process:

BRS is helping me. ... They have someone else working with me now from an agency to take me around and put in applications and things.

Only after being prompted to talk more about the job search, the participant described the job search and acknowledged the job interviews were for positions that ignored the core strengths of her recently acquired marketable skills:

Today I had an interview. It is not in phlebotomy and EKG, but it is something else. ... Well, it is in a nursing home.

This participant had been reluctant to disclose that services contradicted her self-defined goal to make a transition into a new career field, even though she had trained extensively and was 'anxious' to enter the new occupation.

... I was a CNA for 10 years. I worked as a Home Health aide. When I came here, I worked at McDonald's twice. Since then, I took classes. That is when I started my classes in phlebotomy and EKG. ...

Having learned about the phlebotomy career field from an individual in the career, the participant acknowledged, 'I thought I would like it too', completed the training and sought job placement support through services. Even though she experienced having her goals dismissed by her service provider, she appeared hesitant to share the information about her vocational rehabilitation services.

A power differential between the participant and the service provider was illustrated in both the first example of career services counseling and the second example of job placement services. Both participants recalled describing their core strengths and their self-defined goals to their service providers; however, participants experienced services that were not aligned with either their core strengths or their specific goals. The examples illustrate the subordinate position in which participants were located relative to positions of dominance of the staff members providing services. Moreover, the second participant had unintentionally contributed to her own powerlessness in being reluctant to express disappointment or to object to the direction of the services she obtained. As a consequence of the power differential, participants' experiences of services revealed that given their

relative positions of dominance, staff members were dismissive of participants' core strengths and provided services that ignored participants' self-defined goals.

**Powerlessness experienced by participants.** In many participants' accounts, participants described experiences of powerlessness at the system level and at the level of their individual lives. Powerlessness was illustrated at the system level in accounts of the process of staff decision-making about service delivery. One participant recalled experiences of powerlessness in the decision-making process that determined which mental health programs were being funded or eliminated:

I think a lot of services they had for people with Mental Health or people that need services, they omitted it. I know before, they use to have the homemakers come in. They don't have that anymore. A lot of services, they took away. They need to put it back out there because people really need the services. Like for me, I could see where I could benefit from that. They took a lot of that away.

At the individual level, examples are drawn from participants' accounts about their lack of power to influence decisions about their own living arrangements. Powerlessness in the decision to determine where to live was a serious concern from the perspective of one participant who perceived that her place of residence had significant impact on the quality of her life:

I want to live here, but they say they are moving me to ... a facility down the street. It is very small. Some of the apartments don't get sunlight in the window. I don't know if I want to [move] because ... transportation. Staff, they are promising me, my dad was trying to set it up.

Participants also lacked power in the decision-making about roommate assignment, as illuminated in the following the example. The participant described experiencing powerlessness in two ways: She was prevented from selecting the person with whom to share living space and she not well-informed about accessing alternative residential options:

And I have a roommate. You don't choose. You just get assigned a roommate ... share a kitchen, share a bathroom. ... They do have efficiencies that are single occupancy, but I don't know how long you would have to wait for something to open up.

With neither a meaningful role nor a voice to which others listened, participants experienced powerlessness as service recipients in the decisions that impacted the quality of their lives and their recovery. Beyond the challenges of having their voices silenced and ignored and experiences powerlessness within the system, participants described many additional challenges in the recovery journey. These challenges are explored next.

**Holes in the road to recovery: Constraints in accessing resources.** In some accounts, participants sought resources and emotional support for recovery but found themselves following recovery paths that were like rotaries: Circling, visiting and revisiting then-familiar issues, each go-around was rough and painful. For example, one participant described repeated attempts to reach out to family. Each time, the participant experienced a renewed painful perception that his family cared little about him:

I still try and make contact with my family. I call my mom on a regular basis. She won't call me back when I call her. I don't understand why they don't accept me for who I am. ... I do enjoy hanging out with my friends. I will admit that, but that's all I do. ... My family doesn't want anything to do with me ... because I'm sick. ... They don't understand and so I don't have much support on that end.

Impairments of mental illness threw some participants off-course like potholes may cause some bike riders to fall off the path. One participant's impairments from mental illness heightened his fear of having social contact with others. Consequently, during some periods of his life, he lived in self-imposed isolation:

It goes back to the story of being depressed and sometimes I get a little nervous going out someplace. I sort of have a mental illness for this, too. I'm afraid of somebody coming up and trying to rob me or something. I think those thoughts and I get anxiety and scared and stuff. It's something I have to work out. ... I think too much sometimes and I'm – like-negative. Like - say, they're going to Wal-Mart and I'd think about it too much, and then I'd get chickened out sometimes. ... I usually keep to myself.

Juggling limited monthly budgets while managing mental illness or co-occurring disorder, many participants encountered deep holes in the paths they followed paths, so uneven that it was difficult to build momentum toward sustained recovery. For example, there were holes in one participant's budget that constrained her from purchasing a phone and monthly phone services. Consequently, she was unable to access the Warm Line services, a telephone support of peers whose own first-hand experiences with recovery from substance abuse disorder. Without the constraints of a life of poverty, the participant imagined having greater access to resources that would encourage stability in her recovery:

You know, I get clean and I fall off. When I go home at night, that is when it is difficult because there is nobody there. They do have Warm Lines and all that, but it is hard for me to keep a phone. That is another problem that I have, financial. I struggle with that on a day-to-day basis.

Participants provided varying descriptions of the neighborhoods in which they lived. Some participants described living in areas that were rural and distant from transportation resources; some lived in urban areas that were devastated by unemployment, poverty and gangs; some but not all lived in neighborhoods of great diversity. A few participants described neighborhoods that lacked a sense of safety in public spaces; they perceived few places in which they could relax or enjoy nature or exercise. For example, one participant resided in a diverse, urban neighborhood with limited public transportation and perceived that the public park was a resource he could not utilize:

I'm just talking about having fun and I'm not having fun. I'm not really scared or anything. ... The stuff that's going down ... it's a lot different than it used to be in [hometown urban city]. The way things are going on in the streets and parks and the police. Everytime you go out there, the police don't like the ... fighting and drunkenness. ... Sometimes, it could be a little scary.

Thus, many participants longed for social change that would increase broad-based understanding and acceptance of mental illness and co-occurring disorder:

I would like the world to be a caring community and everybody getting along. When someone does something wrong, he could ask for forgiveness. ... I wish the world would be economically developed.

Living in poverty influenced participants' perceptions about the efficacy of medication prescribed for mental illness; it was difficult to adhere to treatment when struggling to pay for the costs of the co-pay. From one participant's viewpoint, ambivalence about medication paralleled his concerns about its out-of-pocket costs:

I don't know if [medications] help or not. I really don't. I would like to get off them because it's costing money to have the prescriptions sent to me. I can't afford it. Just get back to where I used to be before I ever came into a hospital.

To make health care affordable and public spaces safe and accessible, some participants expressed support for government involvement. One participant identified a government-financed solution as the best possible way to alleviate anxiety about health and thus to improve life overall:

I guess medically - insurances. I think we should have free medical, that's what I think. Like Canada. But I would say benefits like that would be, or better able to get benefits, would be much, would be very good. I'd pick something along that line.

Like a biking along a pathway marred by potholes, living in poverty with mental illness was challenging physically and was both emotionally painful and financially difficult as well. Moreover, many participants were restricted in their recovery resources when they were unable to tap into positive family support, adequate finances and safe public spaces. Participants described turning to systems, whether family or friends or the mental health system, to access resources they needed. Sometimes, in reaching out, participants established relationships with others who cared, leading participants to experience a sense of security and safety. There were both perceived benefits and costs of participants' extensive involvement in caring systems. The benefits and costs of that involvement are explored under the next two subheadings.

**Perceived safety and security of caring environments.** Participants described their involvement in many caring environments that included family life, church, college, and the mental health service

system. Reported here are examples of participants' experiences of the mental health agency as a caring environment.

Many individuals expressed the importance of being able to obtain mental health services, since the mental health agency offered participants a sense of being accepted and understood as individuals who experienced impairments related to mental illness or substance use. They contrasted their experiences 'inside' the system with their experiences 'on the outside' where they had experienced ridicule, marginalization and blame for having these very same impairments. Thus, in contrast to the outside world, many participants derived a sense of safety and security from their participation in the service system.

Some participants experienced substantial benefits of being employed within the mental health agency. They described two ways of becoming employed, through being hired into a competitive job or into the Transitional Employment Position (TEP) designated as short-term employment for recipients of social club services. There were not enough clubhouse positions to employ the number of participants who expressed a desire for social club employment. One participant described his feelings about his job application submitted to the agency where he was also a service recipient:

I put in an application to work here in this building; the same kind of job [a TEP worker] is doing in the afternoon shift. ... Cleaning the offices and throwing out the garbage and making sure the garden is straight and everything. And I'm waiting for them to call me. I got my fingers crossed. I want this job. I want this job. ...

In her continuing account, the participant described his reasons for longing to be employed within the mental health agency, reasons that were echoed by many other participants who had similar goals of becoming employees of the mental health system:

I had a tendency of talking loud, and sometimes I don't catch myself and people think that I'm angry and so forth. I want someone to pull me over the side. People at [the mental

health agency] understand me and know me and when they see my voice going up high, they pull me over and they tell me: 'Calm down'. I can use as much help as they can give me when it comes to [that] I'm still learning how to talk with a soft voice.

In the accounts of the few who held jobs in a mental health agency, participants were hired for social club positions. As people in recovery, these participants described commonly shared belief that their employers, as mental health agencies, offered them a sense of safety and security. These participants presumed that their social club employment would not vanish in the event of recurring illness or relapse. One participant acknowledged being under-employed but appreciated his social club job for the atmosphere of acceptance and the low-stress environment that contrasted with that of his chosen profession:

I worked as an electrical engineer [earlier] and that is when I had my nervous breakdown and entered the mental health system. ... It was scary at first because I did not know what was happening to me. I didn't know what was wrong with me. It wasn't until much later that I received a diagnosis. ... and after my mental illness, I had to make some adjustments in my life so that I could work at a much less stressful job and still keep all my benefits. ... Then, that allowed me to gain the confidence to go to cooking school. And I attended cooking school for two years. After I graduated, I asked the clubhouse to hire me as the culinary chef and they did. ...

Outweighing the disadvantages of being under-employed as chef of the social club, the participant perceived that his employment within the caring environment of the mental health agency had added a sense of purpose to his life for many years:

I now work at a clubhouse in [a town] and I am in charge of the lunch program there, so I make lunches for the clubhouse members. I work 4 days a week ... and I am responsible for everything from menu planning to purchasing of food to cooking and preparing the food, helping with setting up the tables, cleaning up, and storing the food, making sure that the food is properly stored, and making sure that everything is clean and sanitized. So, I have been working as the clubhouse food service manager for, I believe it is going to be coming up on 10 years next year ...

The social club was both a gathering place for some participants who were members of the social as well as a workplace for some participants who were among its employees. As members,

participants favorably contrasted the social club with the world outside, finding in the social club a place of refuge that was comfortable, an alternate ‘inside’ world in which caring and reciprocity thrived, a perspective drawn from the account of a participant who was a part-time employee who received wages to perform acts of caring:

I get cleaned up, then I drive to the club and I talk with people. I listen to my boss. ... What I’m doing now is I’m a clubhouse assistant and not really a rehab person. But I do a couple of the things that they do. I will help facilitate a group for somebody who is not in. I will help ... people one-on-one with computer stuff ... help people learn computer literacy.

Mutuality and reciprocity were often described in participants’ accounts of family life, involvement in religious or spiritual endeavors, and social club involvement. Mutuality and reciprocity are social acts through which prosocial emotions are expressed, with prosocial emotions including care, compassion, sympathy and empathy. Participants sometimes described the healing that arose from feeling prosocial emotions and exchanging prosocial emotions with others present at the social club and present in other caring environments of their lives. One participant married and in recovery from substance abuse, described feelings of gratitude for other individuals with whom she has exchanged prosocial emotions:

I am grateful to be here at the [social club]. I’m grateful to have the friends I have and I’m so grateful that I’m clean. I am. I thank God. I thank my family, I thank my husband. I made it and I’m going to continue to be a success.

As illustrated above, many participants referred with gratitude to other individuals who were supportive and trusted, including their mothers in particular and to partners and other family members as well; social club members and staff; therapists; pastors and church members, spiritual mentors, and professors.

Participants often described experiences of relationships that involved mutuality and reciprocity, relational qualities that they perceived promoted healing and recovery. In some

participants' accounts, these qualities were present in the caring environment of the social club and therapy. One participant illustrated the healing that arose from these qualities in describing the treatment relationship in which she cared about the therapist and felt that the therapist cared about her well-being and took time to understand and respond to her needs:

I have a very good APRN that I work with at [the agency]. I think she's one of the best persons, one of the best professionals in her field that I have had. She has been very understanding and she has found the right level of medication for me to take.

For another participant with continuing struggles with drinking alcohol and using substances, caring about her children and enjoying the daily routine of family life provided her with a vision that helped her move toward recovery:

I'd like to get up in the morning, maybe read a meditation out of a recovery book, have a cup of coffee, have some breakfast and maybe take a walk, get some fresh air, exercise, get ready for school. Maybe seeing my kids off to school, coming back home to my kids, coming home to a relaxing evening, maybe a night of family fun, playing a game or something or a nice evening out to dinner or to a movie, and just getting ready for the next day – and being clean.

**Costs of being immersed 'inside' the mental health system.** Some participants described their retreats into the mental health system that contributed to their social isolation and marginalization from mainstream society. For example, in contrast to the caring environment of social club, one participant, also a social club member, described a previous workplace as being deficient in care and concern about the individual worker:

I'd love to work but in the big corporate companies, you always hear of them downsizing. I don't want to get downsized by the [employer] any more. It hurts badly. And I would like to think I could help. I have enjoyed cooking a meal. I enjoyed that.

Immersed within the system of the social club and treatment, some participants experienced diminished in the capacity to cope with the mainstream world. For example, a participant described losing interest in returning after having increased involvement within the social club. The

participant had experienced fear of returning to work after encountering a bullying corporate employer, as described below:

I was hired at Burger King when it first opened. I was employed there for one and a half years. But I stopped working there. It was too stressful. ... After a while, it was too much. They kept adding on more and more.

The participant has described carrying a fear of reentering mainstream employment. The participant was comfortable receiving psychosocial rehabilitation services through the social club that offered a sense of safety and security on the inside. The services were not experienced as helping her to reintegrate into the workplace but to remain socially isolated with other members who also had mental illness and disorders.

When participants held transitional employment positions, they derived a sense of meaning and purpose that vanished upon completing the term of the temporary employment. A participant and formerly employed TEP Van Driver experienced the mental health agency as a caring employer. He noted, however, two concerns about his past employer and present-day service provider agency: first, the agency had not prepared him for the role loss that would inevitably occur at the termination of the transitional employment position. Secondly, the agency did not support him in his transition from paid worker to unpaid social club member:

I didn't lose the [TEP] job, I just completed the term. ... Right now ... my days are ... sporadic, they are never the same. ... I'm staying up until 3 or 4 in the morning and then I fall asleep around 5:00, then I sleep until about usually about noon time. I have been going through that [a lot].

From the perspective of a participant who had worked as a social club chef for more than a decade, his low-stress job offered a sense of safety, security and acceptance. Ironically, these same characteristics of his mental health employment - security, safety and acceptance experienced as an employee 'inside' the mental health agency - had discouraged him from further pursuit of an 'outside' professional career after healing from mental illness onset:

I get paid by the agency, so I get a paycheck every week. ... I have a fairly good paying job. I also have social security disability income, and between the social security and my present job, I do fairly well and I am on all the entitlements. ... I think that the clubhouse staff, the supervisor there, has been very supportive of me. I am grateful that they gave me the chance to work as a chef in the clubhouse, so I think that not only the staff there, but the clubhouse members have been a big help to me to understand my illness and to be supported by other people that understand my illness.

Illuminated through the two previous participant's perspectives were several factors about the caring environment of the mental health agency that have influenced participants to experience under-employment or long-term unemployment. One factor was the perceived financial security of a combination of wages of through part-time social club jobs and 'disability entitlements'. Another factor was the perception that providers of social club and clinical services are more supportive than workplace employers. Ironically, participants experienced that these same staff members ignored the participants' career aspirations, their often under-employed status within the agency as compared to their capabilities; and their needs for social involvement other than agency part-time work. These practices contributed to participants' persistent social marginalization and isolation from mainstream society.

For similar reasons, others participants also constrained their job search activities to the mental health occupational field rather than going 'outside'. Additionally, some participants had developed a collective identity with other service recipients and thus perceived job searches on the 'inside' a safer route to employment:

I have not been using. ... And I've been wanting to come here so I can look for a job. ... I was in Drug Therapy, was coming up there three days a week. More recently, I've been coming up here to [the social club] and I been involved with going to Connecticut Labor looking for jobs. In the fall, I did a semester in school. ... I'd like my days to be filled up with working and going to school, just being normal. I'd like to get into the mental health field or something around counseling, something around substance abuse, something around working with people, something in Human Services.

### **Need for a helpful boost or a caring push toward goal completion or making change.**

Participants benefited from the boost of supportive others, as illustrated from the perspective of a participant whose onset occurred during college:

When I was in graduate school, I considered paper chemistry and got two manic episodes but my professors still stuck with me; when I worked with international paper on an internship program, I had a manic episode and they still stuck with me throughout the state. I worked for a company ... and had a manic episode and they stuck with me. They didn't fire me. ...

Experiences of recovery allowed participants to move beyond notions that they had to be entirely self-sufficient and autonomous, and could build interdependence with others who promoted their healing:

There are a lot of things that can help me. ... I would like to be more self-sufficient, but I know I have been asking for Homemaker services. It's just those periods where I get into a slump and I just need a boost to get back on track.

With diminished confidence about engaging in meaningful 'outside' endeavors, a participant needed a boost to utilize his many talents and skills:

I don't know whether I'm somewhat caught between – seeking a law career and going back to school or getting a law career [and] getting a law career on the spot, getting education – or going back to the janitorial route again. It seems that no matter what I do, there seems to be an impediment somewhere down the line. ... Even though my IQ is supposedly above normal, above average ... I am just an ordinary person with some intelligence ... I just can't figure out why the impediments to my life. ... Mainly my ability to process information .. to dish out information when needed and even to recall information from time to time.

These two participants and many others suggested that sometimes a helpful boost or a caring push was helpful in achieving a goal or making positive change. Without the boost or push from someone outside the self, participants described becoming overwhelmed by their experiences of diminished physical energy, heightened fear and anxiety. Without having a boost or a push from

someone who believed in him, participants described fears and obstacles that presented barriers to their increased involvement in the mainstream:

Getting more money [would improve my life]. I guess it's getting a job. I'm not sure that would be right for me. I'm not very energetic- you know what I'm saying? For a job, I'd have to go every day. Sometimes, right now, there is nothing. ... I start getting dizzy. I think about getting a job one day without this program. Getting a job, it might hurt.

In some accounts, parents and clinical treatment staff members jointly provided a boost and participants described the powerful impact of the boost. First, the participant described his initial grappling with the mental illness that had interrupted his life in college:

I had two jobs, a full course load and a lot of other things cooking at the same time. I was burning both ends of the candle. I had to take a break and see a psychiatrist. He told me I'd get over it., to just take some time off from college which is what I did. ...

The boost was delivered through relationships with several different people who collectively shared a belief in the participant's capabilities and positive worth and encouraged him to embrace a goal-directed orientation:

Somewhere down the line, [someone] says for me to go for it. Three weeks ago, you wouldn't believe what I looked like. I had a captains' beard down to here, a long head of hair and I looked like a green sailor. My father said, 'That's great. You are a green sailor, but nobody is going to like you applying for a job'. You see me with this look and [now] I am completely different.

Several participants received a boost or a push when they learned skills from others. One participant described the boost of 'my mother and different people [who] have been teaching me some budget skills'. Another participant experienced the boost of learning landscaping skills through the support of knowledgeable close others and then becoming self-employed:

I get up in the morning, get dressed, shower and then work all day cutting lawns and raking leaves and cutting down trees. I do landscaping and stuff like that. I do garden work. I come home and work on arts and craft projects that I'm really interested in. I have all kinds of toys to play with and ... I listen to the radio.

From the perspective of another participant, getting a boost equated to being given the opportunities to utilize her skills and to enact her hope of being ‘able to work still on the outside’:

I want to be accepted despite the fact that I’m not 18 or 21 or 25 but that I’m a person that has had at least been there and done that, life experiences that I have gained wisdom from, mistakes that I have made from the decisions I have made, from my past work experience, my volunteer work, and I want to be accepted even when I am 48, 49, or 50 as much as when I was 18, 19, 20.

Some participants desired to be the supportive person who offered a boost to other people:

Being someone who can be a mentor, that can show others- ‘been there and done that’ and can know where they are coming from, especially with the younger people, to realize assuming the roles. ...

Mentoring was a type of boost that participants valued highly. In earlier historical periods, artisan and craft-worker guilds flourished and mentoring and apprenticeships were thriving, although such opportunities have become scarce and competitive in today’s educational and workplace environments. Notwithstanding the competitiveness of the few available mentoring opportunities, participants expressed a desire for mentoring as a boost that would best prepare them to enter the contemporary workplace:

This is one of my big things: I would like to see mentors for people. I looked into the woman at the community college. There was a thing about Advertising in November, a mentorship for students. I did call her and ask if there was anyone like a retired graphic artist who would mentor me and how I would go about doing that. She, unfortunately, didn’t know.

Participants also expressed a desire for On-the-Job-Training (OJT). The ‘OJT model’ of workforce development has faded from popularity along with jobs typical of the Industrial Age. Nevertheless, participants desired opportunities to receive hands-on training in the actual workplace. Participants believed that OJT and hands-on support was likely to improve their prospects for employment and other individual life chances:

On the job-training. I had one a long time ago. But they didn’t have the tools or the money and they didn’t stay long. That’s what the problem was. The only thing I can’t do [is] piece work, because my hands hurt; the dexterity is no good. So training, spending more time to

be with me when I am on the job to just help me out with it. To help me handle the job whatever it is.

Without the boost of being mentored or receiving On-the-Job Training or other types of support, participants encountered many barriers and were unable to enter into the contemporary workplace. Several participants developed a future-oriented viewpoint and planned to obtain credentials or licenses that they believed would provide them with the needed boost to gain entrance into the workforce:

I just want to get my diploma, and what I have intention to study [is] an NA [Nursing Assistant program]. Because I used to be a Nurse's Aide before you had to have a certified certificate. I was working in nursing homes. And as the years went by, you were required a certificate in order to be a nurse's aide, so that's what I'm going for.

One participant perceived that within the mental health system, there were few mentors and few OJT opportunities and services were delivered without a future-oriented outlook:

I feel safe here. ... So that was a realization that I had a week or two ago, that was like wow! No wonder I feel safe here, I have lived here ... for ten years... as long as I've been any place. And you know - the thing is that *nobody talks about future stuff here* - you know - because of the fact that there's no one here that specializes in that stuff. If I can't get to [college] to finish my undergrad, how can I expect them to help me with something like a future beyond [higher education]?

From this perspective, one participant concluded that the sense of safety and security on the 'inside' was an illusion: Having accepted the sense of perceived safety, security and acceptance in the system, the participant recognized that these same characteristics lulled him into contentment without pushing him to find meaning or to make changes to promote recovery.

**Promoting optimal health with additional medical concerns.** Participants' capacities to promote optimal health were complicated by their frequent diagnoses with multiple medical concerns in addition to mental illness. Some of the additional medical concerns included: diabetes,

obesity, lupus, heart conditions, sleep apnea, and blood pressure issues. Participants described feeling blamed and personally responsible for having both their physical and mental health concerns:

I have depression that makes me – I wouldn't say lazy, but it makes me low energy, you know, not wanting to do anything. I think that there's a barrier between me and my case manager because he thinks that I'm capable of so much that he doesn't understand that I'm not. You know, maybe I am. I don't know. But I've tried these things before and they didn't work.

Many participants obtained various forms of treatment to cope with their multiple physical and psychological concerns. Treatment adherence can promote change in one dimension without simultaneously promoting optimal health across all dimensions of concern:

I am in group therapy. But that is not helping my depression. The medication that I switched to has helped me a lot. And I get massive headaches so I take pain relievers for that. They lift the depression. And that has helped me a lot too.

Participants with multiple health concerns described their realization over time that medication had both a potential to help and to harm. Medication side effects impaired the functioning capacity of some participants' bodily organs. For example, some medications affected many participants' biological capacities to process insulin adequately and these participants often developed diabetes. One participant revealed that her self-consciousness about her weight and negative self-image had prevented her from moving toward healthy changes with respect to exercise:

I never go to the pool! I should - [Staff person] needs to recommend me to go there, but because of my weight, I get too embarrassed to go.

With multiple health concerns, participants described difficulties managing symptoms that promoted health and optimal wellness when they lacked information about the nature of chronic diseases beyond mental illness. Chronic disease is typically experienced in cycles of illness which may be followed by periods of remission or a period of prolonged and increasing debilitation. In contrast to demonstrating an understanding the nature of chronic diseases, participants often

expressed the belief that they had been diagnosed and treated for diseases and conditions that they did not actually have:

I have had some health issues. I was diagnosed with leukemia cancer maybe two years ago. I was in the hospital for six months – an operation and bone marrow - they took all kinds of stuff. I felt like I was on my way out and then I got sick last year and they found out I had lupus. ... At the same time, I think I was misdiagnosed. They told me I had lupus and now I don't think I have it.

**Reclaiming life.** Many participants valued the opportunity to reclaim their lives after onset and years of suffering from mental illness or substance abuse. Many participants described the importance of having hope and believing that change is possible, as illustrated below:

I am resetting my life for another 10 years. I'm resetting my life. It's troublesome building your life when you can't go to school, wash your clothes or get food.

Reclamation often involved the pursuit of community college education. Through their educational pursuits, some participants realized that for today's older adult, it was no longer considered non-normative to renew long-deferred academic goals because life trajectories had been interrupted by mental illness or other circumstances, a viewpoint expressed below:

When I went over the community college, most of the people were older than I was at the time. It was like really encouraging because it went against my family's traditional view of what you are going to do at 18 – and you graduate at 22, no later than that, then you go off to grad school. And it's like that's not the real world.

Reclaiming life often involved attending a social club where participants perceived they were cared about and connected to others, which in turn encouraged them to care about themselves, as illustrated in the viewpoint below:

I'd like myself to be leaving substances alone. I've been clean for a couple of days now, which has been difficult for me to obtain, but I think by me coming to the [social club] – that has been helping. I have just been going home, and I haven't been going home just being isolated. ...

Participants' inner resilience combined with their interests and passions were described as contributing to the process of reclaiming life. Illustrating this point is the perspective of a participant who had earlier reported being self-conscious about her significant weight gain. Nonetheless, in planning to relocate to a different town, she approached the change with a spirit of optimism, resilience and hope; she was embracing change as an opportunity to reclaim her life:

I'm moving up to [another town]. There's a pool. I told my fiancée that I don't care what the pool is like, what I look like! ...I like swimming so much; even with my bad back, I can still swim.

Reclaiming life often involved acts of generativity. In developmental psychology, 'generativity' refers both enhancing one's own sense of well-being and also giving back to others, contributing to the quality of life of future generations. Participants who engaged in generative commitments used their time, their skills and talents to making offerings to other people. One participant contributed his expertise to help a friend:

I have always been pretty inquisitive on things like fixing engines and ... I would share thoughts with a friend about how to get his truck running right.

Several participants made offerings of peer support to other members of a social club. From one participant's perspective, generativity was offering compassion and empathy to others as a social club volunteer:

Basically, I am teaching teach classes and [attending] groups... and basically helping people with their recovery. ... Setting goals ... is one of the things that's made my life most fulfilling; ... having something to shoot for, I have one more reason to get up in the morning.

Generative action was also expressed through the advocacy efforts of one participant:

As a person in recovery and having the experience of mental illness and dealing with it, what better person to help and try to make changes in the mental health system. So I have done a lot of advocacy work and it will, I hope, be helpful ...

The same participant recognized that in safeguarding her own recovery, she could make offerings to others by facilitating a support group, thus advancing personal wellness in her own life as well as in others' lives:

I ended up writing a mini grant to start a chapter. ... I knew I would need a support group that met in [my] area. ...

In positive reminiscences about the past, some participants reflected on their earlier generative acts. One participant's generative acts were expressed through having generously shared his artistic talents with others:

I had to balance my good income with the desire [of] helping the world a little bit, so ... every year I did the logo for the ... Museum at ... [a private] University.

In recalling past generative acts through positive reminiscences, one participant longed for present-day opportunities to enact generative concern:

I love helping people if I could. Like you talking to me or helping somebody. What can I do for you ... or visiting people, talking with them. Sometimes you sit there and never know what somebody else goes through until you hear their [stories]. I like to think I used to be a good listener ... because one lady used to tell me, 'Don't go, stay here'.

Many participants demonstrated generative concern by offering consistent caregiving to their aging parents, their children, their pets and their friends. Despite the stress, participants discovered that the rewards of caregiving exceeded the stress and they expressed a longing for more opportunities to express generative concern. This point was illustrated in the account of a participant who was an adult daughter caregiving her aging mother:

I am feeling ... the stress of helping out and taking care of my mother. And helping out with the cats and stuff ... and then dealing with changes in careers and a lot of changes ... so it's kind of a lot of changes in the middle of my life ... I have gained wisdom from the mistakes I have made, from decisions I have made- from my [present] and ... past work and volunteer experience - and I want to be accepted ... kinda like esteemed, being able to be

treated as someone that can be a mentor, that can show others – been there, know where they are coming from – especially with younger people ... assuming the roles ...

It was important for participants to achieve balance: on one hand, paying attention to self-care and well-being throughout the processes of maturation and aging; and on the other hand, following through with opportunities to help others. The point was illustrated in one participant's example of balancing self-care with her volunteer work as a peer support advocate:

... it kind of divides my time. Because of depression and anxiety, I only have limited energies. When I focus out on other people, then I am not focusing on myself. Right now, as the BRS person said, it's a full-time job just trying to get a job. For now, I think I need to get myself into a position. ...

In the final example, a combination of resilience, self-care and spirituality were reflected in a participant's account of what had helped most in reclaiming her life:

Resiliency. Realizing I'm a survivor and not a victim. God. My Higher Power. ... And regardless how tiny it is, I still have hope. Knowing I want to live. I really don't want to die, even though I felt that way. I don't want to die, I want to live. And I guess I'm worth it. Deep down inside.

**Recommendations:**

Individuals' needs must be addressed through a holistic and well-integrated approach; the understanding of needs must be derived from a developmental perspective.

- a. Participants' emotional and mental health were inextricably integrated with physical health. However, they perceived their experiences being divided according to types of service they received. Services were oriented primarily toward the professional's discipline. Inadequate attention was given to the holistic nature of human experience.
- b. Reflective of a developmental perspective, participants described variously their experiences as maturing young adults, elders who were aging, adult children who were caring for aging parents and children. It is recommended to orient service delivery around the developmental process and to discourage professional perspectives that are tightly constrained by the standpoints of discreet disciplines.

Inter-institutional support must be enhanced for the successful employment of individuals in recovery from mental illness and substance.

Partnerships such as Connectivity have been previously established among the Connecticut Department of Mental Health and Addiction Services (DMHAS), the Bureau of Rehabilitation Services (BRS), and the Department of Labor (DOL) and are commended as early starts. These partnerships must be enhanced in several ways:

- a. Increase the number of relationships established across the various institutions. Through inter-institutional relationships, knowledge about workforce trends can remain current; workforce demands are shared and understood; and doors can be opened, new opportunities can be created, particularly for work that holds meaning for the individual.

- b. New and creative inter-institutional strategies must be developed to increase the preparedness and the stress management skills of individuals with illnesses and disorders. Difficulties handling stress in the workplace contributed to under-employment and long-term unemployment. Individuals may become ill and unable to work in a chosen profession while healing from illness or disorder. As the healing occurs, individuals' capabilities and interests change. Strategies are needed to individualize supported employment services according to the individual's capabilities and interests as they change and grow over time.
- c. Demonstrate the outcomes of inter-institutional partnerships and strategies: Repeatedly mentioning that work provides meaning and structure for life, participants understood that being employed was an essential indicator of personhood and responsible adulthood in American society. Increases must be shown in the number of service recipients who enter the workforce and retain the jobs *for which they are qualified* in the contemporary workforce.
- d. Establish opportunities for mentoring, coaching, and on-the-job training (OJT) *within the businesses and agencies* where the jobs are located. Many participants possessed degrees that qualified them to enter professions that included electrical engineering, graphic design, and phlebotomy. Interruptions of mental illness often caused a gap between college degree and last period of employment in the chosen occupation; re-entry was difficult since skills and knowledge acquired earlier in college may have become obsolete. If employed at all, these participants were under-employed, although many had remained unemployed for years. Job placements in high-level occupations were appropriate for individuals with high-level skills and education. Thus, job development efforts must include the development of high-skills jobs as well as low-skills jobs. Supported

employment staff of DMHAS-funded vocational services lack the necessary expertise to provide job coaching in high-level technical and professional areas. Coaching and mentorship opportunities can be explored through retired professionals and through the businesses directly.

Perspective-taking skills are essential to person-centered planning. Services funded by DMHAS and BRS must develop practices, procedures and trainings designed to eliminate the silencing participants' voices and ignoring their strengths and interests.

- a. Institutional commitment is needed to define services according to the individual's self-defined needs and to conduct decision-making within the system that effectively includes service recipients' perspectives.
- b. Advocates must organize service recipients, must conduct widely attended forums and must create additional venues with the input of partnering institutions (including DMHAS, BRS and DOL).
- c. Additionally, training and professional development must be provided to increase all staff members' skills in perspective-taking skills.

Through listening to individual's voices, responding to individuals' self-defined needs and increasing perspective-taking skills, *person-centered planning can be truly implemented.*

Prosocial emotions are essential to healing and must be incorporated into services. Participants' accounts reveal that the path to recovery is long and difficult; their experiences revealed that treatment can both help and harm.

- a. Compassion and empathy are emotions that helped participants to recover and reclaim their lives.

- b. Prosocial emotions such as compassion and empathy must be an ongoing intentional part of program design and service delivery in every state agency that provides services to individuals with mental health and substance use concerns.
- c. Generativity promoted healing as expressions of prosocial emotions. Generativity was experienced as the sense of well-being and the sense of contributing to others' well-being. Social rehabilitation and other services must encourage service recipients to develop awareness of generativity. Commitments to be generative can be widely encouraged; acts of generativity can be acknowledged when they are performed.
- d. Mutuality and reciprocity were qualities in relationships that promoted healing. These qualities should be encouraged in relationships between social club members and as appropriate in relationships of providers with service recipients.

Training and information about inheritance law and disability rights must be widely disseminated.

Individuals with psychiatric disabilities and their family members appear to lack knowledge and resources to protect family wealth for future generations.

Structural features of services must be eliminated that promote the social isolation and marginalization of service recipients as individuals with illness or disorders.

Serious consideration must be directed toward the design and delivery of present-day social and vocational rehabilitation services.

- a. The Individual Placement and Support (IPS) model assists some individuals to experience job placements, but one model is not likely to meet the needs of every individual service recipient. Some participants needed much more support than was available to them through vocational and psychosocial rehabilitation. Existing services must develop and implement new models and additional supports that can be address the range of service recipients'

needs along a continuum of services. Examples include pre-employment skills; relationship-building founded on trust and caring through which an affirming push or a helpful boost to make a meaningful difference.

- b. Social clubs practices that facilitate a sense of security and safety were appreciated by participants; however, social club involvement must also facilitate members' development of self-awareness and skills. Current expectations of social clubs must be examined. Establish what social clubs are doing. Explore how social clubs can help some participants to reduce their perceived dependence or their habit of relying primarily upon the social club environment for social interactions and meaningful lives. Social clubs must play a role in helping individuals reduce their experiences of social isolation and marginalization from mainstream society. For example, social clubs can support the development of pre-employment skills, such as overcoming fear and social anxiety of the mainstream workforce.
- c. Providers and service recipients must develop increased awareness of the sense of safety and security derived from 'inside' the system. There must be dialogue about the costs of the sense of safety and security in terms of individuals' increased isolation and marginalization from the 'outside', mainstream society. From this dialogue, ideas may arise about how social clubs can support the development of individuals' of prosocial emotions through having contact and linking with others of similar interests and emotional connectedness. These may include building ties with spiritual or religious seekers, establishing family or family-like relationships, inclusion in associations of writers or poets or musicians or hikers.

This concludes the report. For discussion of findings and recommendations, contact Marcia DuFore, Executive Director of the North Central Regional Board.