

**CONNECTICUT**

**MENTAL HEALTH  
TRANSFORMATION**

**WORKGROUP 2:  
MENTAL HEALTH CARE IS  
CONSUMER AND FAMILY DRIVEN**

**June 2006**

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## I. Introduction

The scope of the *Mental Health Care is Consumer and Family Driven* Workgroup's charge was at the same time daunting and exciting. Under Goal 2 of the President's New Freedom Commission (NFC) on Mental Health are such transformation objectives as person-centered and individualized treatment, self-directed services, interagency coordination, collaboration and accountability, streamlining federal/state regulations, promotion of braided funding streams, recovery supports (i.e., housing and employment), and consumer rights and protections. All of these initiatives are extremely important and worthy of considerable reflection in any mental health transformation effort. Fortunately, Workgroup members were equal to the task at hand coming from varied backgrounds, experiences and perspectives. This diversity provided richness to the contemplations and discussions that led to the final recommendations and strategies.

As with the other Mental Health Transformation State Incentive Grant (MHT-SIG) workgroups, our charge was to: 1) analyze preliminary needs assessment data, b) identify the successes and challenges facing Connecticut's mental health and related service systems, and c) based on the preliminary needs assessment and the NFC goals, and perspectives of advocates and consumers, make recommendations on how best to transform Connecticut's mental health system. In part, these objectives were met, with a qualifying statement. Every attempt was made to make the process open and inclusive so that the broadest perspective and constituency input was gained. Membership was wide-ranging (see Section III for details) and open to all interested persons with particular emphasis on having significant family and consumer representation. Nonetheless there was a noticeable lack of youth representation. Youth participation proved difficult due to the timing of meetings. To counter this void of a very important voice, not just in this Workgroup but across others as well, opportunities were made available to youth (e.g., Transitional Youth & Young Adults *Turning 18 Conference*, Department of Children and Families' Youth Advisory Council, and other venues) in order to gain their input.

From the beginning of the process, the Workgroup was given background documents that would set the vision and direction. One important document was the recently released Substance Abuse and Mental Health Services Administration's (SAMHSA) *National Consensus Statement on Mental Health*. These *10 Fundamental Components of Recovery* set the tone for discussion, forged the vision to be achieved, and will provide the basis for measuring future success of a transformed mental health system that is consumer and family driven. The 10 fundamental components of a recovery-focused mental health system are:

1. **Self-Direction** - Consumers lead, control, exercise choice over, and determine their own path of recovery.
2. **Individualized and Person-Centered** - There are multiple pathways to recovery based on an individual's unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background.

3. **Empowerment** - Consumers have the authority to choose from a range of options and to participate in all decisions including the allocation of resources that will affect their lives, and are educated and supported in so doing.
4. **Holistic** - Recovery encompasses an individual's whole life, including mind, body, spirit, and community.
5. **Non-Linear** - Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience.
6. **Strengths-Based** - Recovery focuses on valuing and building on the multiple capacities, resiliencies, talents, coping abilities, and inherent worth of individuals.
7. **Peer Support** - Mutual support including the sharing of experiential knowledge and skills and social learning plays an invaluable role in recovery.
8. **Respect** - Community, systems, and societal acceptance and appreciation of consumers including protecting their rights and eliminating discrimination and stigma are crucial in achieving recovery. Self-acceptance and regaining belief in one's self are particularly vital.
9. **Responsibility** - Consumers have a personal responsibility for their own self-care and journeys of recovery.
10. **Hope** - Recovery provides the essential and motivating message of a better future – one which recognizes that people can and do overcome the barriers and obstacles that confront them.

Various other documents were incorporated into the knowledge base upon which the Workgroup drew from for understanding, direction and inspiration.

Overall, the most striking dimension of the process was the interest, enthusiasm and commitment that all participants brought to the task before them. This is best summarized by one member who stated that she “cleared her calendar” to attend Workgroup meetings because she found them to be informative, thought provoking, and a forum for new and shared ideas. This commitment to being engaged in and contributing to a transformation of Connecticut’s mental health system based upon the values of consumers and families is evident by the substantive recommendations brought forth by the Workgroup.

## **II. Workgroup Process**

A series of six meetings were held between March and May of 2006 with a Workgroup totaling 40 members of which 37 were “active members”, i.e., those who attended at least one meeting. A complete membership list is attached (see Attachment A: Goal 2 Membership List). Attendance across the six meetings averaged 22 (61%) members, with the lowest being 16 and the highest 29. A few members, while wishing to participate, had scheduling conflicts or in one case lacked transportation that prohibited their involvement. Of the active members, two are advocates in the adult system, seven are child or family advocates, 10 are consumers, two are family members of adult children with a serious mental illness, five are service providers, and eleven represent various state agencies. Most of the members are not defined by one constituency group, but rather have several different roles in which they interact with the mental health system. For instance, they are a family member who is a mental health professional or a mental health worker who is a consumer. Rather than clouding their perspective, members with

multiple connections to the mental health system afforded a greater depth of understanding of the challenges faced and possible solutions.

The objective of the meetings was to develop a consensus vision on recommendations and strategies aligned to the New Freedom Commission's Goal 2: Mental Health Care is Consumer and Family Driven. As part of that process, needs and barriers were explored regarding Connecticut's current mental health service system. A variety of resources were referenced by the Workgroup including Yale University's ACCESS database containing findings from numerous published reports. This repository of findings contained a broad range of topics related to the NFC goals and other relevant areas of interest. These "data bits" were mined from such important reports as the Department of Mental Health and Addiction Services' Priority Services Report, the Governor's Blue Ribbon Commission Report, the Community Strategy Board Report, the Community Mental Health Services Block Grant State Application, and the Prison and Jail Overcrowding Commission Report, to mention a few.

Prior to breaking into smaller discussion groups, Workgroup members were introduced to the Mental Health Transformation-State Incentive Grant (MHT-SIG) goals, purpose and vision. Specifically, the Workgroup reviewed the NFC's Goal 2 objectives (or subgoals), the scope of the MHT-SIG (e.g., that it encompass the lifespan, be limited to funding non-direct service activities, etc.) and discussed their view of the task before them. To assist in "brainstorming", they were asked to engage in a process known as the "Affinity Matrix". This is a creative process that produces a range of ideas. It is most helpful when the task at hand is considerable, involves multiple stakeholders, breakthrough thinking is required and time is short. Workgroup members were asked to write on "post-its" challenges/issues and visions/strategies as related to the NFC's Goal 2 subgoals and in particular how they affected the individual, family, community and system. This process was completed without discussion as Workgroup members pasted their comments on easel paper under each related subgoal. The members' remarks were then placed in a document that was distributed for review. Additional comments were solicited from those members not in attendance and other stakeholders. Through this process, the Affinity Matrix became a reference document, continually expanded upon, as the Workgroup engaged in discussion and crafted its recommendations.

At the first meeting, some members felt that there was inadequate representation from the children's system of care. Several members, including staff from the Department of Children and Families (DCF), offered to bring more family members into the Workgroup. Issues remained as how to involve youth. Additionally, some members felt that the adult and children's mental health systems used terminology that implied different meanings and perspectives. Therefore the second meeting was devoted to orienting members to the two service systems with presentations on DCF's "local systems of care" and collaboratives, and the status of the adult's system in reference to NFC's six transformation goals. A third presentation from a Department of Mental Retardation staff focused on that department's initiative to provide consumer choice through self-directed services. These presentations grounded Workgroup members in a common understanding of Connecticut's current mental health system, allowing the process to move forward.

At this point, the Workgroup was offered several alternative methods to draft recommendations. This included forming small working committees that would meet between the larger Workgroup meetings. The majority felt that meeting outside the scheduled Workgroup times would be difficult. Instead they opted to break into smaller discussion groups, meeting during the regularly scheduled time allotted for bi-weekly Workgroup meetings. Several members volunteered to lead these groups with two facilitators for each discussion group.

Discussion groups within the Workgroup were formed around NFC subgoals including: 1) Consume Empowerment, 2) Consumer Involvement in Planning, Evaluation and Services, 3) Coordination and Accountability, and 4) Consumer Rights and Protections. Each discussion group used the results from the Affinity Matrix as a point of departure to begin the dialogue. The discussion groups met twice, with a portion of each meeting devoted to reporting on draft recommendations to the entire Workgroup. This process continued, and as recommendations were refined they were sent to the entire Workgroup for comments.

The last two meetings were set aside for final review and discussion. Workgroup comments were incorporated into all draft recommendations. Convener staff consolidated recommendations where there was overlap, or in cases where the recommendations were truly a string of strategies. This was done to allow for easier prioritizing of recommendations by the Workgroup. The final recommendations were sent out to all Workgroup members who were given **10 priority points**. These priority points could be used in any combination that members wished, for example using all 10 on one recommendation or spreading the points out across 10 recommendations. There was no overriding criteria used for prioritizing recommendations and they solely represent the perceived importance that the member held on one recommendation versus another. Final priority scoring was calculated by adding the number of points across recommendations (see Attachment B: Recommendations Priority Scoring). It should be noted that the scoring took place by e-mail and a total of 18 (49%) members actually responded.

### **III. Needs, Vision and Recommendations**

In the following narrative, “**consumer**” is used to mean a person receiving mental health services which could be either an adult or youth. The term “**those that support consumers**” refers to a parent(s) or guardian for a child receiving mental health services or a family member or friend of an adult receiving mental health services.

#### **Subgoal(49%) 1.1**

#### **Develop an Individualized Plan of Care for Every Adult with a Serious Mental Illness and Child With a Serious Emotional Disturbance (Consumer Empowerment)**

Subgoal 1.1 of the NFC’s Goal 2 focuses on individualized treatment plans, but the perspective it encompasses has a far greater vision of consumer empowerment. In this respect, all aspects of how consumers are cared for in the mental health service system were explored. Certainly, person (includes youth)-centered approaches to mental health services are at the heart of this transformation objective, with individualized treatment plans being but one component of a broader strategy.

***“You keep talking about getting me in the ‘driver’s seat’ of my treatment and my life... when half the time I’m not even in the damn car!” - quote from a woman in recovery on her experiences of treatment planning (Tondora, et al).***

The importance of this consumer’s statement is that several very important elements need to be in place prior to being able to “drive” or in this case direct one’s care. While there has been a significant shift over the past several years of treating mental illness from a disease-oriented to a recovery-oriented perspective, consumers still lack some of the basic “skills” needed to move them into the “driver’s seat”. Consumer empowerment brings with it a need for informed choices and with that the requisite training and supports. Both providers (from agency directors to line staff and others such as educators) and consumers must be given the tools necessary to successfully accomplish this system change.

The Workgroup identified the following challenges or barriers to Consumer Empowerment:

- Lack of choice in the system (medical necessity vs. consumer choice services)
- Consumer belief that he/she does not have the right to decide and perception that people with a mental illness will never be able to construct a meaningful [treatment] plan
- Lack of support and assistance to families from the beginning to understand and participate in planning services for their child
- Need to improve coordination of services for families and children across all involved organizations/agencies
- Lack of leadership and commitment
- Defining “Self Determination” as it relates to people as opposed to systems
- Individual Plans of Care need to be dynamic (ever-changing) not a paper product completed then put away in a drawer
- Children are often difficult to diagnose with a particular mental illness due to developmental issues
- System oriented approach to understanding the family and mental illness is needed
- Providers need to be more educated on I.D.E.A. (Individuals with Disabilities Education Improvement Act) and be available to assist parents

In response to these challenges facing Connecticut’s mental health system, the Workgroup identified a vision of what could be. Some of these include:

- Consumer goals across life domains should be the primary driver in the Treatment Plan in the person’s own words - something the person is proud of, feels ownership over and has the resources needed to draw others into helping promote and sustain his/her recovery
- Increase staff training to promote the move towards a person-centered system of care
- Help consumers navigate “the system” - consumers should have choices and the right supports to make those choices
- A solid commitment from the Commissioners to adjust budgets to a self-determined system
- Re-educating professionals by not having an “authoritative role” over a person in treatment

- Every provider organization should have a staff position (paid or volunteer) who's sole job is to help that agency move to a more consumer- and family- driven model of practice
- Create a comprehensive database of agencies and services to assist consumers and those who support them understand their choices – develop a “menu” of services that persons in recovery can choose from
- Develop a practice model that requires a “wrap around” approach to each child/family/consumer. Each child/family/consumer chooses their own team including both natural/informal supports as well as paid professionals
- Provide access to more trained family advocates to assist in the process and support families to participate in planning services for their child
- Develop a behavioral health workforce that understands the concept of healthy family systems and family dynamics, and also understands the family experiences of recurrent illness across family development and over the lifespan
- Promote a workforce that continues to address an individual's treatment needs and includes the family and, in addition, addresses the family's need for education and support beyond treatment issues

Out of this came a unified vision:

***Develop a strength-based, seamless, local, community-based, culturally competent, and consumer-driven, inter-agency system of care that crosses all state departments and meets the emotional, behavioral and mental health needs of all consumers (adults and children) and those that support them (family, friends and others).***

Recommendations to achieve the vision include:

1. Create a common set of values that are consistent with the President's New Freedom Commission on Mental Health regarding person- (including youth) centered treatment planning and consumer choice to serve as the guiding foundation to be incorporated into state agencies' and provider organizations' missions and day-to-day operations.
2. Implement an assessment process that is: comprehensive, strength-based, culturally competent, and consumer and goal-centered (including life skills).
3. Promote a more flexible funding system for treatment dollars in order to align finances with consumer-driven goals and consumer directed services.
4. Establish and promote a statewide consumer advocacy movement.
5. Develop incentives to adopt and ultimately mandate the use of a consumer satisfaction survey (for children and adults) that is effective and a process that uses the information.
6. Design and implement a self-determination (self-directed) pilot for adults with mental illnesses and children with serious emotional disturbances using lessons learned and models employed from national pilots (SAMHSA-funded) as well as Connecticut's Department of Mental Retardation (DMR).

Each of these recommendations require that consumers be fully engaged as active participants (i.e., having a major representation) in transforming Connecticut's mental health system. In that process, consumers and those that support them must be involved from the very beginning in determining the core values, guiding principles and vision statements essential to

Connecticut's mental health service system becoming truly consumer and family driven. State agencies that are responsible for the delivery of mental health services (either directly – operate or indirectly – fund) will ensure that these consensus values are embraced and are the cornerstone to all mental health services provided through their auspices.

In order to achieve this far reaching transformation, several incremental steps (or strategies) are required. First, an evaluation of the current status of Connecticut's mental health system in relation to the consensus core values developed on consumer-driven principles must be carried out. Through this review, resource needs can be identified aiding the development of a training curriculum and provision of other supports. The curriculum will be designed to train and educate the various stakeholders (e.g., state agency staff, provider organizations, educators, and others) who currently administer, manage or deliver services for those with a mental illness. Several state agencies have experience in rolling out such service system changes and their knowledge can be utilized in this effort. Essential to the success of this initiative will be ongoing training of new staff and reinforcement of concepts over time. Additionally, an evaluation component as to the effectiveness of the training, i.e., acceptance and implementation of consumer-driven and directed service values, must be part of the implementation design from the beginning.

Lastly, there was a strong voice advocating for consumer choice through implementation of a self-determination (self-directed) service model for DMHAS and DCF consumers and families. Certainly this recommendation embraces wholeheartedly the concept of a recovery model that is truly a consumer- and family- driven service system. The principles upon which self-determination is built goes to the very essence of changing the way consumers and those that support them are thought about and how they think about themselves (SAMHSA, 2003). Within a self-determination model are the essential ingredients that speak to a service system that is transformed and has at its core a focus on peer supports. It also promotes real choice and control over services, and recognizes the central role that consumers and those that support them play in all aspects of policymaking, planning, and evaluation of services (SAMHSA 2005). That said, an important aspect to any consumer directed service system is ready access to effective education and an array of support tools to assist the consumers (Armstrong, Mary I., 2004).

Five basic principles of self-determination (Nerney, 2004) provide the foundation that support this change and include:

1. Freedom –the opportunity to organize all the important aspects of one's life;
2. Authority – the ability to control some proportion of public service dollars;
3. Support – the provision of resources that allows for individualized services;
4. Responsibility – the requirement to use public dollars wisely; and
5. Confirmation – the affirming that individuals with disabilities must play a significant role in redesigning the service system.

Needed changes in the service system cut across many current practices including budgeting, consumer education and coaching, access and choice within the service network, quality improvement and funding sources. Within this recommendation are many opportunities for the

MHT-SIG grant to support and promote its success that are related to infrastructure building. Fortunately, there are several existing model from which to create such a redesigned service system that reflects consumer- and family-directed choice.

**Subgoal 2.2:**

**Involve Consumers and Families Fully in Orienting the Mental Health System Toward Recovery: Consumers and Families are Involved in the Planning, Evaluation and Delivery of Services**

Certainly subgoal 2.2 is at the very heart of the NFC goal of consumer and family involvement. While there has been a range of advocacy activities over the years in Connecticut, and increasingly so, there is a sense that the depth and breath of consumer and family involvement could be deeper and broader. At least in more concerted ways. Again, as in the previous subgoal (2.1), there are a number of perquisites needed to guide and nurture involvement. Additionally commitment on the part of government, provider and other key organizations to encourage, support and value consumer and family involvement is essential to the success of the initiative.

Barriers and challenges identified by the Workgroup to fully involve consumers and families in the mental health system include:

- Meeting times for planning and evaluating are not always convenient for families and caregivers
- Families and consumers are not always compensated appropriately when they “come to the table”
- Need to identify, educate and support children, families and consumers who would like to participate in planning and evaluating
- Respect for consumers
- Multiple priorities of work and school are sometimes a barrier to involvement by consumers and those who support them
- Lack of leadership and commitment
- Lack of interest and time on the part of families or consumers
- Involving families in the development, implementation and evaluation of programs requires support, both financial and through leadership training and mentoring
- Need to involve mental health consumers in planning so that services actually mirror needs
- Multi-stakeholder input is not consistently sought when contemplating new services or program changes. That which is gathered may be compiled for review but rarely is reflected in strategic planning, quality improvement priorities or responded to in a formal way.

The vision realized to address these barriers includes:

- Promote cross-disability advocacy as persons with mental illness usually have multiple issues they are dealing with
- Pay consumers for their time and work, develop a simple reimbursement system for families and consumers for their time and dedication
- Make a true commitment to consumer and family involvement

- Provide support to family advocacy organizations to train and mentor parent consultants - pay stipends to parent consultants and expand the current system
- Retrain staff to respect the perspective of consumers and families
- Contact representatives of existing self help groups and customize these community groups to fit the needs of a person in recovery
- Have consumers involved from the very beginning of the evaluation process by identifying measures and outcomes
- Provide a leadership academy to build skills of consumers to be leaders

A major component of consumer and family involvement is consumer-driven services (CDS). These service programs include a significant contribution from mental health consumers in the design, administration, executive leadership, and/or service provision. They vary widely in focus, size and the degree to which consumers are involved in day-to-day programming and development. The essential characteristics of CDS are universal however—any CDS program must feature active participation of consumers as a regular part of its planning process, and input from these individuals must be of foremost importance in decision-making. According to SAMHSA-funded research, common ingredients to consumer-operated services are organized under the categories of Structure, Belief Systems, and Process. Under Structure, one key ingredient was found to be that “staff consists primarily of consumers who are hired by and operate the COSP” (consumer-operated service provider), and that consumers decide all policies and procedures. The environment of the program is an important part of Structure, and includes the element of safety from “threat of commitment, clinical diagnosis, or unwanted treatment.” Remaining environmental elements are accessibility, informal setting, and reasonable accommodation.

A wide variety of organizational settings may lend themselves to CDS programs and related activities, from large mental health service agencies to unique grassroots efforts run on a volunteer basis. Some, but not all, of these organizations have consumer involvement as a part of their charter or mission statement, for instance requiring that there be majority consumer participation on Boards of Directors or staff. Many CDS are completely independent, incorporated organizations. Others may operate under a nonprofit umbrella framework, within a traditional provider agency, or even as part of an inpatient hospital program. In Connecticut, there are several programs that are consumer-run including peer-to-peer vocational services and peer-supported transportation and to a lesser degree consumer-operated such as Advocacy Unlimited or FAVOR.

Persons in recovery and family members provide unique insight and experience into the process of recovery and effective strategies for navigating systems of care and support. Nonetheless Peer Specialist and Family Advocate roles are often of limited scope, under funded or in the case of adult consumers result in dead end or tokenized employment opportunities.

Employment opportunities for consumers and family members should exist at all levels in Connecticut’s mental health advocacy and service systems. Additionally, Peer Specialist roles currently don’t afford opportunities for career advancement. There should be mechanisms and structures that assure ongoing professional education, career counseling, and assistance in continuing or completing formal education for consumers employed in the state’s mental health service system.

Recommendations developed by the Subgoal 2.2 discussion group include:

1. Require state-run programs and state-contracted provider agencies to demonstrate significant commitment to gathering and utilizing multi-stakeholder input in their performance planning processes, program evaluation activities and strategic goal setting as a condition of continued funding.
2. Promote and support meaningful employment of self-identified persons in recovery and family members in the mental health service system providing value-added support to quality improvement initiatives. Support peer employment roles that allow opportunities to accumulate experience and education needed to advance along a career path.
3. Provide tangible support to Connecticut's statutory advisory and oversight bodies, in conjunction with community advocacy and grassroots organizations, in being fully involved in planning and evaluation initiatives. These activities should be coordinated to assure maximize effectiveness through the adoption of standard protocols for planning and evaluation as well as outcome measures.
4. Develop peer and family-operated programs to deliver services and assist in planning, program evaluation and quality improvement activities with assistance from state-run and contracted agencies.

These recommendations cover a broad spectrum of initiatives transforming Connecticut's current mental health system to one that has consumers and families at its very core. Recommendation 1 sets into motion a process that would firmly establish consumer and family involvement as a mainstay in how Connecticut plans, evaluates and delivers mental health services. Under this recommendation, a multi-stakeholder group would be formed to create and adopt "Principles of Involvement". This set of guidelines, in turn, would provide the minimum expectations that state agencies and contracted providers are measured against for involving consumers in roles related to planning and evaluation of mental health services. Within these minimum expectations are performance standards that address how consumers and families involved in these initiatives are selected, trained and supervised, and supported in other material ways (mileage, stipends, childcare). The intent of the "Principles" is to assure that minimum standards and practices are in place that maximizes consumer and family involvement and to provide guidance to the mental health service community in reaching this objective. The recent release of DMHAS' Practice Guidelines for Recovery-Oriented Behavioral Health Care and DCF's work in the recent past around collaboratives and local systems of care (KidCare) can serve as preliminary principles for broader discussion.

As such, State agencies and contract providers would be required to demonstrate their adherence to these principles including evidence that consumer input was acted upon. Assistance would be available to state agencies and contracted providers in developing competencies in this area. Trained evaluators would assess how well the "Principles" were actually adopted and put in practice. Evaluation staff would include families and consumers.

A similar process would be established for **peer-provided or peer-operated** services. A set of minimum standards and criteria or governing principles would be established including assurance of employment roles that offer upward mobility through gained experience and training opportunities. An essential component of this recommendation would be appropriate

training and credentialing of all paraprofessional roles, including peer specialists. Areas of competency would include recovery-oriented care and practical skill building in navigating treatment and support systems. Credentialing will require expectations for ongoing education and potential external review to address grievances or complaints of staff performance. Lastly, the credentialing process would be tied, in a collaborative manner, with higher education and licensing bodies. In that way training taken through the credentialing process would earn college credits.

The discussion group briefly reflected upon Connecticut's statutory advisory and oversight structure. As there are many such defined entities with strong grassroots support, the discussion group felt that the involvement of these bodies regarding planning and evaluation (including setting outcome measures) would be critical. Currently there are a multitude of agencies and advisory groups that appear to create unique approaches to such activities but may lack the expertise to advance their efforts. In order to make certain that these bodies work in a coordinated manner guidelines and/or technical assistance regarding planning and evaluation activities would be established that promotes involvement of consumers and families.

Also explored by the discussion group was the need to communicate Connecticut's mental health transformation vision broadly across the provider and consumer and family communities. This recommendation is not, in some ways, different than that recommended by the Consumer Empowerment discussion group. Its focus is on promoting consumers' and families' direct involvement in shaping (and reshaping) the mental health system across the more encompassing range of planning, evaluation and services. To that end, the discussion group envisioned State-sponsored technical assistance (TA) being provided within the existing network of consumer and family entities. The focus of the TA would be to encourage and facilitate the development of resources and skills leading to more expansive consumer and family involvement. Particularly, the TA would be directed at development of peer-operated services and delivered through existing provider and consumer- and family- directed organizations, for example, Connecticut Community for Addiction Recovery (CCAR), Advocacy Unlimited (AU), or FOR-U.

### **Subgoal 2.3:**

#### **Align Relevant Federal Programs to Improve Access and Accountability for Mental Health Services**

Certainly recommendations under the NFC's subgoal 2.3 on improved access to and accountability within mental health services has the possibility to transform Connecticut's mental health system in very significant ways. That is not to say that the State has not laid the groundwork for this to happen. Interagency collaboration has been a major component of Connecticut's strategy to improve mental health and recovery support services over the past decade. Starting with the Blue Ribbon Commission on Mental Health, followed by the Mental Health Policy Council and Community Mental Health Strategy Board, cross-system collaboration has been strongly emphasized as key to making substantial inroads to improving the Connecticut's mental health system.

Included under this subgoal is housing and employment – or more appropriately what might be called – a sustained recovery through a life in the community. Without a doubt, housing and employment (and transportation although this workgroup didn't focus on it) are absolutely essential to a recovery-oriented mental health system. Across the state, affordable, safe housing is severely limited or totally unavailable for many of the persons receiving publicly supported mental health services (DMHAS, 2004). Forces contributing to this problem include an increased housing demand brought on by an aging and depleted housing stock, commercial development such as gentrification, and zoning restrictions including stigma – Not In My Backyard - all of which have contributed to the present situation. Lack of housing in general impedes the recovery process creating gridlock, adding to the number of persons receiving inappropriate care in more restrictive settings (Office of Protection and Advocacy for Persons with Disabilities, 2004; Connecticut Mental Health Cabinet Report, 2005). This need is reflected across both the adult and children's system (DCF, 2004). While recent efforts, such as DMHAS' PILOTS program and the Connecticut Coalition to End Homelessness, have helped to mitigate the problem there remains a dire need to provide more housing opportunities so that consumers and families have a range of housing options.

A number of barriers or system shortfalls exist that must be addressed if housing is to be readily available and within reach of consumers and families. Many individuals and families who could benefit from current housing programs do not know of their existence and therefore cannot benefit from them. Other barriers to affordable and safe housing exist as well. For instance, the federal government is providing less subsidy funding, in the form of Section 8 vouchers, to assist in the payment of rent. Federal and state agencies use different definitions and eligibility criteria, and there is inconsistency in application of rules. On the other hand, local Public Housing Authorities have experience in managing housing that is dedicated to serving disabled populations and that is coordinated with DMHAS provided mental health services.

Along with housing, having a choice of employment options is key to promoting self-sufficiency and a feeling of hope. While over 70% of persons with a mental illness identify employment as a key component of their recovery and sense of community belonging, less than 15% are working - the lowest rate of all disability groups. Nationally only 5% of persons with a mental illness have access to supported employment services. In Connecticut approximately 10% of consumers receive employment services of various kinds. However, some regions of the State have achieved levels of 22% or higher where this service has received a high priority. Transformation activities have the potential to raise the statewide average considerably, as is demonstrated in certain areas of the state currently.

A “recovery-oriented” approach recognizes that the majority of people desire and are capable of employment. Many consumers are discouraged from working or are told they are “not ready” to work because providers and family members fear that the stress of work will destabilize their recovery or they will lose their medical benefits. Others who are working are frequently clustered in low wage, entry-level positions regardless of their skills and desires. While evidence-based employment practices have been documented to yield two times the rate of job placement, retention, and earnings outcomes, they are only used by five agencies in Connecticut. The employment barriers that limit access to the kind of jobs consumers want are

changing. For instance, recent modifications in benefits legislation make it more likely that consumers can keep their medical benefits as a safety net as they return to work. In the end, respecting individual choice requires that multiple pathways to employment be valued and made available.

Recommendations offered by the discussion group include:

1. Streamline and coordinate regulations, guidelines and funding relevant to people with mental illness for treatment, housing, vocational rehabilitation, and other recovery-oriented services across state agencies to improve access and accountability.
2. Improve access to services through a Consumer/Family/ Provider-friendly resource information system to increase knowledge of and access to a range of recovery-oriented services through appropriate behavioral, physical health and social service resources.
3. Build systems that increase hopefulness among consumers, family members and treaters regarding recovery and the possibility of competitive employment and self-sufficiency by: raising awareness of the positive role of employment, assisting consumers to advance in their careers, and increasing the visibility of employment and educational opportunities.
4. Increase individual consumer choice in employment while offering encouragement and pre-vocational activities to those who may feel they are not ready.
5. Increase levels of interagency coordination by leveraging community-based employment resources, identifying and disseminating best practices across all systems, and building transition protocols between key agencies (e.g., DMHAS and DCF).
6. Increase accountability through the measurement and tracking of employment outcomes.
7. Make decent, safe, affordable housing units available statewide through a marketing campaign regarding development of a statewide resource list and collaboration with existing advocacy efforts.
8. Review state and federal housing policies and regulations to promote efficiencies and streamline procedures.
9. Provide housing training and education for housing as well as clinical services staff.
10. Provide more housing opportunities for young adults transitioning out of youth status.

Due to time constraints and the need for greater cross-agency representation, strategies concerning streamlining regulations and braided funding streams did not receive adequate attention. The recommendation of the discussion group was to form an interagency task force to examine federal and state programs and regulations including client eligibility, policy and financing, as well as investigate ways to increase collaboration and coordination. Some preliminary strategies included: transforming the way in which state agencies provide mental health and supportive services to be aligned with the recovery model through education, training and collaboration; expanding the DMHAS collaborative contracting model to encompass more joint funding of mental health and support services; developing public/private partnership with Foundations and United Ways on braided/blended funding; and integrating clinical system for clients with co-occurring mental health and addiction disorders.

A range of strategies was suggested by the subgoal 2.3 discussion group addressing ways to create more housing options for persons with mental health disabilities. These strategies employ collaborative partnerships, streamlining eligibility criteria, and information

dissemination. Some of the strategies are to: promote awareness of the need for housing through advocacy efforts and a marketing campaign, develop an electronic inventory of available housing units throughout the state, work collaboratively through the “Reaching Home” initiative to review per unit cost of housing and determine possible cost savings, require all federal and state funded housing to follow federal inspection guidelines and provide greater access to rental assistance certificates.

Many of the housing strategies build off existing structures be it local housing authorities, advocacy efforts, or interagency collaborations. Most are infrastructure driven and fit the requirements of the MHT-SIG for allowable costs such as developing and implementing training and education modules. Others target specific populations in critical need such as young adults transitioning from the DCF system to DMHAS who may be entering the community after many years of institutional care.

As with housing strategies, employment strategies address a number of areas that target improved access to services (training staff, family members, consumers and others in recovery-oriented practices, resources, Americans with Disabilities Act and worker rights), promoting employers who hire persons with a psychiatric disability, system changes in attitudes and perceptions (information dissemination such as newsletters highlighting success stories) and relationship building across systems (convening a local interagency taskforce to articulate collaborative linkages, coordinating funding streams and cross-training staff). Also emphasized is use of peers to provide ongoing encouragement and supports, and inclusion of consumers and family members in all employment planning. Career counseling must also be provided to insure that consumers’ skills and desires drive the employment process and facilitate career advancement. Major inroads have been made in developing a strategic vision to employment of persons with a mental illness. Nonetheless the discussion group identified areas needing special attention such as support for young adults as they enter the job market (and even youth prior to becoming young adults), promoting best practices, and training on small business startup and peer-run businesses.

**Subgoal 2.4:  
Create a Comprehensive State Mental Health Plan.**

This subgoal was not part of the Workgroup charge.

**Subgoal 2.5  
Protect and Enhance the Rights of People with Mental Illnesses.**

Under subgoal 2.5 of the NFC’s report are a number of objectives that speak to the rights and protections of persons with a psychiatric disability and children with serious emotional disturbances. Among these are: fully integrating consumers into their communities under the *Olmstead* decision, eliminating conditions under which parents must forfeit parental rights so that their children with serious emotional disturbances can receive adequate mental health treatment, eliminating discrimination based on past assignment of a psychiatric diagnosis or mental health treatment, and reducing the use of seclusion and restraint in mental health treatment settings.

In 2003, after a Hartford Courant article brought to light the reality of using restraint for persons with psychiatric disorders, SAMHSA's Administrator, Charles Curie, stated that: "Seclusion and restraint should no longer be recognized as a treatment option at all, but rather as a treatment failure." SAMHSA then set forth a vision and a plan to reduce and ultimately eliminate seclusion and restraint from treatment settings for mental and addictive disorders. In addition, the Center for Medicare and Medicaid Services' (CMS) Conditions of Participation, for all types of hospitals as well as for psychiatric residential treatment facilities for individuals under age 21, established standards for use of seclusion and restraint. Both sets of standards include the following requirements:

- Prohibiting their use as coercion or discipline;
- Excluding their use for any reason but to ensure safety in emergency situations (and emphasizing that only approved methods should be used in those situations);
- Requiring staff and consumer debriefing and reporting of any deaths; and
- Requiring staff education and training.

Since that time, Connecticut along with the nation has examined its practices in the use of seclusion and restraint. Staff training and establishment of revised protocols has resulted in reduced application of seclusion and restraint. In spite of that, the discussion group noted that while there has been success in lowering the overall number of restraint hours, there remains some concern regarding uniform application in the reduction of restraint. Also, de-escalation training exists but should be repeated to assure continuous reinforcement of alternatives to the use of restraint.

The discussion group also examined broader issues of general knowledge of rights and protections, and Americans with Disabilities Act (ADA) compliance. Currently many people (consumers, family, friends, neighbors, employers, employees, etc.) in Connecticut dealing with mental illness are not aware of their rights under the ADA, the concept of recovery, self directed care or the importance of advance directives for mental health care emergencies. Neither are they aware of the Department of Protection and Advocacy for People with Disabilities or other agencies that could provide information and/or assistance. In addition, some State agencies have not fully completed Self- Evaluations and Transition Plans as required under the ADA. These self-evaluations must examine ADA compliance in four general areas including operations, effective communication, employment and program/facilities accessibility. Lastly, some agencies have not developed a means of ensuring contractor compliance with the State's obligations under the ADA.

On another front, consumers are becoming more involved in recovery planning, developing advance directives, utilizing grievance processes and otherwise exercising their rights. There is an increased need for advocacy assistance that may not be generated solely by consumer complaints. This will require a more coordinated approach to assure the rights of persons with a psychiatric disability are known and upheld. For instance, legislation passed in the 2006 General Assembly, (Public Act 06-195), modifies prior statutory language regarding advance directives and health care decision-making. The Public Act amends and updates Connecticut law on health care decision-making by expanding the scope of a living will and the authority of

the health care representative. Training for consumers about differences in Advance Directives, Wellness Recovery Action Plan (WRAP) and Person Centered Planning is necessary so that they fully understand the intended use and application of each in taking charge of their recovery process.

The discussion group made the following recommendations:

1. Require all state agencies and any entity and/or individual contracting with the State or applying for licensure to provide mental health services to inform individuals served by them of their rights regarding psychiatric disabilities.
2. Enforce full compliance with the Americans with Disabilities Act (ADA) for all agencies in Connecticut.
3. Expand and strengthen the Office of Protection and Advocacy's role in promoting consumer empowerment and involvement.
4. Create an interagency (DMHAS, DPH, DCF, , Department of Correction (DOC), Department on Aging) Joint Division of Community Education and Recovery Affairs to better coordinate activities related to the rights and protections of persons with a psychiatric disability.
5. Promote the awareness and use of advance directives throughout the state so that persons with mental health disorders are better informed and able to communicate their preferred treatment choices.
6. Adopt a policy across all state agencies of a goal of zero use of restraints.
7. Promote awareness of mental health rights and responsibilities through a coordinated and comprehensive media campaign.

Specific strategies under the first recommendation requiring all state agencies and those contracting with the state to inform persons served by them of their rights regarding psychiatric disabilities include:

- Distributing a copy of consumer/customer handbook which shall contain a description of consumer rights and the agency's obligations to consumers under state and federal law.
- Displaying posters describing consumer's rights under state and federal law.
- Developing a rights education plan for consumers, staff and community that includes:
  - a schedule for and description of how consumers will be informed of rights upon admission and periodically thereafter,
  - a description of training that will be provided to new and existing staff on an ongoing basis, and
  - a schedule and description of trainings that will be provided to consumers, and those that support them along with a sample of curriculum and materials.

Regarding full compliance with the Americans with Disabilities Act (ADA), relevant state agencies include DMHAS, DCF, DOC, and the Department of Social Services. These agencies must complete their Self-Evaluations assessing employment, effective communications, general operations, and program and facility accessibility. This also encompasses assessing contractor

compliance with the State's obligations under Title II of the ADA. For DMHAS and DOC, this means addressing equal opportunity of alternative incarceration for individuals with psychiatric disabilities. Possible use of MHT-SIG funds would include hiring of a consultant(s) or other ADA experts to help facilitate compliance by implementing and facilitating the completion and execution of Self-Evaluations and Transition Plans.

A majority of one meeting was devoted to discussing expansion and strengthening of the Office of Protection and Advocacy's (OPA) role as it relates to promoting consumer empowerment including increased opportunities for volunteer advocates. One strategy includes posting notice of volunteer and paid positions in mental health facilities, social clubs, and community newspapers. Another strategy promotes actively seeking mental health consumers to fill vacancies on the Board of Directors. Other suggested strategies are: include more mental health consumers as staff in professional and para-professional positions, increase types and availability of advocacy services (i.e. assistance with advance directives, recovery and planning, addressing issues of conservatorship) and increase publicity about OPA and its mission.

As was true in the other discussion groups, the Rights and Protections discussion group recommended the formation of an interagency committee to review current state agencies' mission statements, goals and strategic plans. This body, meeting regularly, would also be responsible for disseminating literature (program descriptions, brochures etc) and identifying gaps and overlaps in protection and rights activities. This committee would then develop ways to improve the State's system of consumer rights and protections in an ongoing review of needs and applied solutions.

Another area of intense interest that the discussion group focused on intently was consumer directed illness management. Over recent years, self-management programs have been developed with the most widely accepted being Mary Ellen Copeland's Wellness Recovery Action Planning (WRAP). WRAP is a program in which consumers identify resources that will facilitate their recovery, and then create their own, individualized plan. Generally speaking, individuals are encouraged to develop a crisis plan indicating how they wish to be treated in times of crisis. A WRAP is similar to an advance directive as both provide a post-crisis plan for getting back on the road to recovery. There is general confusion as to the differences between Advance Directives, WRAP and Person Centered Planning. More training for consumers is needed so that they understand the differences between these mechanisms for conveying their personal treatment choices and preferences. The discussion group also recommended that Connecticut establish a statewide Advance Directives Registry within the Secretary of the State's Office in collaboration with DMHAS and other relevant agencies.

As was mentioned above, Connecticut has made great strides in the reduction of seclusion and restraints over the past few years. Nonetheless, ongoing support is needed to continue this effort to assure that it is lasting. Particularly supporting ongoing de-escalation training to staff based upon the work already in place will provide a stronger focus on changing the institutional culture to one that is restraint free.

Another aspect of this discussion group's recommendations deals with a media campaign. These media events should be educational and cover client/consumer/patient rights, rights of

family, rights of guardians/conservators, rights of parents with mental illness, advance directives, care/treatment planning options, how to file complaints or grievances, where to go for assistance, and how to access advocacy services. Other suggestions include: hiring an advertising/media consultant and convening small work groups across the state consisting of interagency rights specialist and media personnel with client/consumer and mental health advocates to work on spot and print development.

#### IV Conclusion

Many of the needs identified and recommendations offered by the Goal 2 Workgroup have been echoed in numerous reports, studies and policy documents. While not completely new, the work produced by this dedicated and diverse group of professionals, consumers, families and others represents a concerted effort to move Connecticut's mental health system to one that has consumers and those who support them at the very heart of person-centered care and recovery. It is an attempt, through the lens of the NFC vision, to tie the threads of consumer involvement, empowerment and choice into a supportive network that truly sees the individual consumer and those that surround him/her as the essential ingredients to a sustained recovery.

Many of the recommendations recognize that we all must be at the same point of departure in moving the State forward. Therefore a number of recommendations begin with convening a stakeholder group to examine where we are now, where we want to be, and how we can get there (and know that we have arrived). We are fortunate that some of the groundwork has been completed and that the underpinning of many of the concepts discussed in this report has been explored with thoughtful consideration. What is needed now is focused attention across the many stakeholder groups that make up Connecticut's mental health recovery system. A coordinated effort aligned to a uniform vision is what's called for – exactly what the MHT grant is intended to promote and in the end make possible.

Still there is work to be done. The recommendations, constructed out of the collective knowledge of the Workgroup members, are a great beginning but they are just that - a start. More discussion and consideration, particularly regarding the actual implementation, is needed. More consumers, families, youths and others need to be brought into the process to take on the hard work of fashioning recommendations into reality.

## Attachment A: Goal 2 Membership List

Mary Ellen	Breault	CT Insurance Dept.
Sheryl	Breetz	North Central Regional Mental Health Board
Glenna	Butler	Catholic Charities
Lucia	Catalano	Med Options
Molly	Cole	FAVOR, Inc.
Christina	Colon	STAR Mentoring
Tony	Corniello	Harbor Health Services, Inc.
Kristin	Dowty	Department of Social Services
Zosh	Flammia	Family Focus Partnership - Waterbury
Steven	Fry	Department of Mental Health and Addiction Services
Gary	Grabko	Capitol Region MH Center
Ruth	Howell	Department of Mental Health and Addiction Services
Merva	Jackson	African Caribbean American Parents of Children w/Disabilities
Karen	Kangas	Department of Mental Health and Addiction Services
Ronna	Keil	Department of Mental Health and Addiction Services
Lyn	Lawrence	Southeastern Mental Health Authority
Elizabeth	Lazariel	Western CT Mental Health Network
Ken	Littlefield	St. Lukes Lifeworks
Cristina	MacGillis	Office of Long Term Care Ombudsman
Melissa	Marshall	Advocacy Unlimited Inc
Tim	Marshall	Department of Children and Families
Debbie	McCusker	Family Focus Partnership - Waterbury
Lilianna	McIntrye	Department of Public Health
Daniel	O'Connell	CT Council of Family Service Agencies
Joanne	O'Connor	Recovery is Hard Work
Ed	Pantano	Yale University
Diana	Pierce Murray	Family Focus Partnership
Jim	Pisciotta	Southwest CT Mental Health System
Marya	Pyrek	
Priscilla	Ridgway	Yale University
Nayda	Roper-Lemay	Capitol Region Mental Health Center
Janet	Shepard	Department of Mental Health and Addiction Services
Elliot	Stone	Department of Mental Health and Addiction Services
Mark	Suplinskas	Department of Veteran Affairs
John	Torello	Judicial Branch/CSSD
Jossie	Torres	Department of Mental Retardation
Nancy	Urgell	We Can
Robin	Wood	Department of Mental Retardation

## Attachment B: Recommendations Priority Scoring

Recommendations/ Objectives: Workgroup 2	Priority Ranking
2.1.1. Create a common set of values that are consistent with the President’s New Freedom Commission on Mental Health regarding person- (including youth) centered treatment planning and consumer choice to serve as the guiding foundation to be incorporated into state agencies’ and provider organizations’ missions and day-to-day operations.	1 (tie)
2.1.3. Promote a more flexible funding system for treatment dollars in order to align finances with consumer-driven goals and consumer directed services.	1 (tie)
2.2.2. Self-identified persons in recovery and family members are meaningfully employed in the service system to fulfill the continuum of care and provide value added support to quality improvement initiatives. Peer employment roles are well supported and allow opportunities to accumulate experience and education needed to advance along a career path.	3 (tie)
2.2.4. Develop peer and family-operated programs to deliver mental health services and promote consumer involvement in planning, program evaluation and quality improvement activities with assistance from state-run and contracted agencies.	3 (tie)
2.1.6. Design and implement a self-determination (self-directed) pilot for adults with mental illnesses and children with serious emotional disturbances using lessons learned and models employed from national pilots (SAMHSA-funded) as well as Connecticut’s Department of Mental Retardation (DMR).	5
2.1.4. Establish and promote a statewide consumer advocacy movement.	6 (tie)
2.5.4: Create an interagency (DMHAS, DPH, DCF, DOC, Department on Aging) <b>Joint Division of Community Education and Recovery Affairs</b> to better coordinate activities related to the rights and protections of persons with a psychiatric disability.	6 (tie)
2.5.7: Promote awareness of mental health rights and responsibilities through a coordinated and comprehensive media campaign.	8
2.3.1. Streamline and coordinate regulations, guidelines and funding relevant to people with mental illness for treatment, housing, vocational rehabilitation, and other recovery-oriented services across state agencies to improve access and accountability.	9 (tie)
2.3.2. Improve access to services through a Consumer/Family/ Provider–friendly resource information system to increase knowledge of and access to a range of recovery-oriented services appropriate behavioral, physical health and social service resources.	9 (tie)
2.5.2: All agencies in Connecticut must be in full compliance with the Americans with Disabilities Act (ADA).	9 (tie)
2.1.2. Implement an assessment process that is: comprehensive, strength-based, culturally competent, and consumer and goal-centered (including life skills).	12
2.2.1. State-run and contracted provider agencies are required to demonstrate significant commitment to gathering and utilizing multi-stakeholder input in their performance planning processes, program evaluation activities and strategic goal setting as a condition of continued funding.	13 (tie)
2.2.3. Statutory advisory and oversight bodies, in conjunction with community advocacy and grassroots organizations, are materially supported in being involved in planning and evaluation initiatives and coordinate activities to maximize effectiveness. These entities should play and incipient and significant role in developing outcome and performance measures.	13 (tie)

Recommendations/ Objectives: Workgroup 2	Priority Ranking
2.3.5. Increase levels of interagency coordination by leveraging community-based employment resources, identifying and disseminating best practices across all systems (DMR, DCF, BRS, DMHAS, DOL), and building transition protocols between key agencies (e.g., DMHAS and DCF).	13 (tie)
2.3.3. Build systems that increase hopefulness among consumers, family members and treaters regarding recovery and the possibility of competitive employment and self-sufficiency by: raising awareness of the positive role of employment, assisting consumers to advance in their careers, and increasing the visibility of employment opportunities.	16 (tie)
2.5.1: Require all state agencies and any entity and/or individual contracting with the State or applying for licensure to provide mental health services to inform individuals served by them of their rights regarding psychiatric disabilities.	16 (tie)
2.5.3: Expand and strengthen the Office of Protection and Advocacy's role in promoting consumer empowerment and involvement.	18 (tie)
2.5.6: Adopt a policy across state agencies of a goal of zero use of restraints.	18 (tie)
2.3.7. Make decent, safe, affordable housing units available statewide through a marketing campaign regarding development of a statewide resource list and collaboration with existing advocacy efforts.	20 (tie)
2.5.5: Promote the awareness and use of Advance Directives throughout the state so that persons with mental health disorders are better informed and able to communicate their preferred treatment choices.	20 (tie)
2.3.4. Increase individual consumer choice in employment while offering encouragement and pre-vocational activities to those who may feel they are not ready.	22 (tie)
2.3.6. Increase accountability through the measurement and tracking of employment outcomes.	22 (tie)
2.3.9. Provide housing training and education for housing as well as clinical services staff.	22 (tie)
2.3.10. Provide more housing opportunities for young adults transitioning out of youth status.	22 (tie)
2.1.5. Develop incentives to adopt and ultimately mandate the use of a universal consumer satisfaction survey (for children and adults).	
2.3.8. Review state and federal housing policies and regulations to promote efficiencies and streamline procedures.	

Note: Those recommendations with an **equal number** of votes resulted in ties and were scored with the same rank.

**Attachment C: MHT-SIG: Workgroup 2: Mental Health Consumer and Family Driven – Affinity Matrix**

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
<p><b>Consumer &amp; Family Empowerment</b></p> <p><u>Rec. 2.1:</u> Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.</p>	<ul style="list-style-type: none"> <li>• Individualized and customized plan of care: Genuine opportunity to construct and maintain meaningful, productive, and healing partnerships with consumers, families of children with SED, clinicians and other providers.</li> <li>• Address consumers needs and preferences; consumer directed services.</li> <li>• Improve coordination.</li> <li>• Achieve and sustain recovery.</li> <li>• Provide TA to each consumer/family of child with SED.</li> </ul>	<ul style="list-style-type: none"> <li>• (Adult Provider Perspective) Medicaid Rehab option medical necessity vs. client choice about specific services.</li> <li>• Respect for Consumer Desire within the system.</li> <li>• Adequate \$\$ for long term care</li> <li>• Consumer belief that he/she does not have the right to input.</li> <li>• Families need support and assistance to participate in planning services for their child.</li> <li>• Improving coordination of services for families and children involved organizations/agencies (like health, education, informal community groups) who are not at the table.</li> <li>• Find out if it's a physical illness not a mental illness "misdiagnosed".</li> <li>• Status quo Medical Model.</li> <li>• Lack of Leadership and commitment.</li> <li>• Changing attitudes. Perception that some people w/MI will never be able to construct meaningful plan.</li> <li>• (Child) Believe they "know what's Best" for children &amp; families. For patients with private insurance, there may be a conflict between patient's/physician's desired plan of care and what the insurance carrier deems to be medically necessary.</li> </ul>	<ul style="list-style-type: none"> <li>• Adult: WRAP (Wellness Recovery Action Plan).</li> <li>• Consumer goals across life domains should be the primary driver on the Treatment Plan in the person's own words.</li> <li>• Adult: Help consumer navigate "the system".</li> <li>• People should have choices in provides and should be able to fire their workers.</li> <li>• Have a solid commitment from the commissioners to adjust budgets to a self-determined system..</li> <li>• Child: Have every provider organization have a staff position (paid or volunteer) who's sole job is to help that agency move to a more consumer &amp; family driven model of practice.</li> <li>• Get a true definition of self-determination.</li> <li>• People need help by a navigator through complex systems.</li> <li>• Adult &amp; Children: Need database of agencies and services.</li> <li>• Decision-making aides must be developed to help people make choices among treatments.</li> <li>• Education of service recipients to know options/choices</li> <li>• Child: Develop a practice model</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
Consumer & Family Empowerment		<ul style="list-style-type: none"> <li>• Lack of Education in communities.</li> <li>• Define “Self Determination” as it relates to people as opposed to systems.</li> <li>• Individual Plans of Care need to be dynamic (ever-changing) not a paper product completed then put away in a drawer.</li> <li>• Have each individual complete a physical to rule out physical problems that might have contributed to the mental illness.</li> <li>• (Adult) Challenge to individuals &amp; their families: During early years of raising child w/SED, family members &amp; system of care may “do for” in providing care for the child. This may lead to: family’s needs apart from child’s treatment needs being overlooked. When child of family enters adult system that empowers the person, they may choose not to include the family in treatment. But family still cares but has little to no interaction w/system yet family continues to have needs that go unmet.</li> <li>• (Adult) Family of young person who experiences first episode needs information and support. Resource options seem (in rural areas) limited to support of NAMI or therapy. Family needs are not easily met.</li> </ul>	<p>that requires a “wrap around” approach to each child/family/consumer. Each child/family/consumer chooses their own team including both natural/informal supports as well as paid professionals.</p> <ul style="list-style-type: none"> <li>• (Child) Need to develop a bridge with Education to work them into a plan of care for children with serious emotional needs. Also have someone attend meetings with individual family planning teams.</li> <li>• Educate providers in the importance of S.D. (Self Determination) for consumers.</li> <li>• (Child) More education on SED living in community and schools.</li> <li>• Provide access to more trained family advocates to assist in the process and support families to participate in planning services for their child.</li> <li>• Increase support to local systems of care for kid’s mental health to expand and support broader participation.</li> <li>• Individual plans of care is something the person is proud of, feels ownership over and has the resources needed to draw others into helping promote and sustain recovery.</li> <li>• Educate Consumer/Family as to the desired goal.</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
<p><b>Consumer &amp; Family Empowerment</b></p>		<ul style="list-style-type: none"> <li>• Children often difficult to diagnose with a particular mental illness</li> <li>• Respect children with mental illness</li> <li>• Address issues of what constitutes family (extended family vs. family of origin)</li> <li>• System oriented approach to understanding the family and mental illness</li> </ul>	<ul style="list-style-type: none"> <li>• Create “menu” of services that persons in recovery can choose from.</li> <li>• Persons in recovery have access to providers 24 hours daily until person is comfortable to be discharged.</li> <li>• Child: SED. Schools need better understanding of SED, have a more positive structure - child should not be provoked with behaviors.</li> <li>• Staff Supervision- Training to always include component that promotes better understanding of client/recovery to promote increased respective.</li> <li>• Staff training and increased staff support to allow mistakes to be made and corrected.</li> <li>• (Adult) Behavioral health workforce understands healthy family system and family dynamics, and also understands family experiences of recurrent illness across human/family development over lifespan.</li> <li>• Therefore, workforce can engage both the individual and the family where they are developmentally. Workforce continues to address individual’s treatment needs and includes family and in addition addresses family’s need for education and support beyond treatment issues.</li> <li>• Navigator for consumers and families for the complicated system.</li> <li>• Providers be more educated on the</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
			<p>I.D.E.A.</p> <ul style="list-style-type: none"> <li>• Providers be available to assist parents of children at I.E.P. meetings.</li> <li>• Facilitated to families on their rights under the I.D.E.A.</li> <li>• Have embedded consultants in every program who are trained about recovery who can advise other clients and clinicians about how to set up recovery oriented plans and approaches.</li> <li>• Have people in recovery be major part of a team to travel to evaluate every program. Create “report card” assessment device to assess how well programs are moving toward a recovery model and have way to give feedback on needed changes. Ideally, have funding or other benefits contingent on doing better with this.</li> <li>• Need to be able to categorize or recognize mental illness with children</li> <li>• Recognize that children have needs that need to be cared for.</li> <li>• Be able to accommodate the needs of all types of families.</li> <li>• Recognize the dynamics of the system and how it affects the family.</li> <li>• Be able to accommodate the needs of all families.</li> <li>• Navigator for consumers and</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
			<p>families for the complicated system.</p> <ul style="list-style-type: none"> <li>• Providers be more educated on the I.D.E.A.</li> <li>• Providers be available to assist parents of children at I.E.P. meetings</li> <li>• Facilitated to families on their rights under the I.D.E.A.</li> <li>• Have embedded consultants in every program who are trained about recovery who can advise other clients and clinicians about how to set up recovery oriented plans and approaches.</li> <li>• Have people in recovery be major part of a team to travel to evaluate every program. Create "report card" assessment device to assess how well programs are moving toward a recovery model and have way to give feedback on needed changes. Ideally, have funding or other benefits contingent on doing better with this.</li> </ul>

Address the Categories across:

- Individual
- Family
- Community
- System

**MHT-SIG: Workgroup 2: Mental Health Consumer and Family Driven**

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
<p align="center"><b>Consumers &amp; Families Involved in Planning, Evaluation and Services</b></p> <p align="center"><u>Rec. 2.2:</u> Involve consumers and families fully in orienting the mental health system toward recovery.</p>	<ul style="list-style-type: none"> <li>• Develop recovery–oriented services.</li> <li>• Support consumer-run organizations services (e.g. peer-support &amp; psychosocial rehabilitation programs.</li> <li>• Involve MH consumers in planning &amp; evaluating quality of MH care.</li> <li>• Support research on self-help, recovery, and empowerment.</li> <li>• Promote evidence based consumer operated services.</li> </ul>	<ul style="list-style-type: none"> <li>• Recovery orientation needs to occur outside of the system – all objective listed focus on mental health stakeholders.</li> <li>• (Child) Meeting times for planning and evaluating are not always convenient for families and care givers.</li> <li>• (Child) Families/Consumers are not always compensated appropriately when they “come to the table”.</li> <li>• (Child) Identifying, educating, and supporting children families, and consumers who would like to participate in planning and evaluating etc. to change the system.</li> <li>• Improve parity issues between primary medical care and MH/SA care (services)</li> <li>• Challenge: Really! Respect for consumers</li> <li>• Multiple priorities work/school etc..</li> <li>• Re-educating professionals by not having “authoritative role” over person in treatment</li> <li>• Providers having caseload that is unmanageable.</li> <li>• Don’t try to make adult and children’s system of care the same.</li> <li>• Challenges: Finding the time and</li> </ul>	<ul style="list-style-type: none"> <li>• More cross disability advocacy.</li> <li>• Child: Develop simple system to reimburse families/consumers for their time and dedication to particular issue.</li> <li>• Have Commissioners make a TRUE commitment.</li> <li>• Statewide provider database that includes target population, exclusionary criteria.</li> <li>• Pay consumers for their time and work.</li> <li>• Provide support to family advocacy organizations to train &amp; mentor parent consultants. Pay stipend to parent consultants. Expand current system - models are available for this.</li> <li>• (Child)Educate people in the community to help explain to the every day consumer what is out there for them and how to open the door to them.</li> <li>• Retrain staff to respect the perspective of consumers and families.</li> <li>• Contacting representatives of existing self help groups and customizing these community groups to fit person’s in recovery</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
		<p>money to do these things.</p> <ul style="list-style-type: none"> <li>• Knowledge of need (Insight)</li> <li>• Lack of leadership and commitment</li> <li>• Lack of Interest/time of family or consumers.</li> <li>• Involving families in the development, implementation and evaluation of programs requires support, both financial and through leadership training and mentoring.</li> <li>• Services have not been focused on recovery therefore the system needs to be revised.</li> <li>• Need to involve mental health consumers in planning so that services actually mirror needs</li> <li>• Family may find difficulty with having the time to be involved in planning</li> </ul>	<p>needs.</p> <ul style="list-style-type: none"> <li>• Empowerment evaluation includes consumers identifying measures and outcomes.</li> <li>• Leadership academy to build skills of leaders.</li> <li>• Adopting a recovery oriented system that sees the family as the focus and plans for changes that occur due to mental illness</li> <li>• Address issues of planning with family within group therapy sessions.</li> </ul>

Address the Categories across:

- Individual
- Family
- Community
- System

**MHT-SIG: Workgroup 2: Mental Health Consumer and Family Driven**

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
<p><b>Improve Access &amp; Accountability: Sustain Recovery - A Life in the Community</b></p> <p><u>Rec. 2.3:</u> Align relevant Federal (and State) programs to improve access and accountability for mental health services.</p>	<ul style="list-style-type: none"> <li>• Examine federal and state programs including eligibility, policy and financing.</li> <li>• Coordinate and streamline regulations &amp; funding guidelines. Funds follow the individual.</li> <li>• Increase levels of interagency coordination.</li> <li>• Promote respite care services for caregivers.</li> <li>• Develop supported employment.</li> <li>• Promote Individual Placement and Support - employment planning.</li> <li>• Provide more opportunities for competitive job.</li> <li>• Reduce barriers to supportive employment and promote education outreach.</li> <li>• Use Supportive Housing model.</li> <li>• Identify housing barriers to address chronic homelessness, Section 8 &amp; public housing policy.</li> <li>• Provide adequate MH services in correctional facilities.</li> <li>• Develop appropriate jail diversion and re-entry transition</li> </ul>	<ul style="list-style-type: none"> <li>• How separate mental health and substance abuse is.</li> <li>• (Child) Improve access to services for kids and families!</li> <li>• (Child) Parents/caregivers are not aware of or educated about the services that are available.</li> <li>• Good paying, interesting work.</li> <li>• Definition of housing.</li> <li>• Adult: Safe affordable housing for those who need it most.</li> <li>• Funding for housing.</li> <li>• Challenge: How to set-up a standard form to collect data on them.</li> <li>• Housing – not affordable.</li> <li>• Challenge: Adult and Child: Several agencies/providers providing similar services but not aware of others.</li> <li>• Low wage rates.</li> <li>• Affordability of housing.</li> <li>• Challenge: Adult &amp; Child: Lack of mental health professionals employed by the courts.</li> <li>• One central office for either consumers/family member to go to find out information about all programs instead of “Trial &amp; Error” searching.</li> </ul>	<ul style="list-style-type: none"> <li>• Behavioral Health Services Mental Health (MH&amp;Dual diagnosed) and Substance Abuse (Primary) across the life span.</li> <li>• Coordination with housing providers.</li> <li>• Consistency of housing standards.</li> <li>• Flexible funds should be available to individually tailored supports.</li> <li>• Consumer preference should drive housing &amp; vocational choices – based on needs and preference.</li> <li>• Peer mentors are needed.</li> <li>• Share staff between agencies as liaisons.</li> <li>• Coordination with housing developers.</li> <li>• Home/condo ownership.</li> <li>• Improved transportation systems.</li> <li>• Child: Diversion programs children need access to more programs, before they hit the juvenile justice system.</li> <li>• Have business mentoring.</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
<p><b>Improve Access &amp; Accountability: Sustain Recovery - A Life in the Community</b></p>	<p>programs.</p>	<ul style="list-style-type: none"> <li>• Families repeatedly tell us that they begged for help for their children for years and by the time they got help their child was in the juvenile justices system.</li> <li>• Avoid re-inventing the wheel. Listen and learn from other state agencies or services who are already doing something well, i.e., support employment and housing.</li> <li>• Determination of appropriate housing for individual consumers.</li> <li>• Defining mental illness in understandable language-that focuses on child family and larger system.</li> <li>• Consistency in addressing concerns of provider and needs of consumer</li> <li>• Provide sufficient on going training that focuses on recovery issues.</li> <li>• Look at the difference between mental health and mental illness</li> <li>• Supportive housing model needs to address issues of mental illness that effect adequate family services.</li> <li>• Defining mental illness in understandable language - that focuses on child family and larger system</li> </ul>	<ul style="list-style-type: none"> <li>• Train more peers and families as staff</li> <li>• Higher paid jobs not just food, filing and filth.</li> <li>• Work with <u>schools</u>, get them to the table to better identify and support children - not divert them to other system.</li> <li>• Have nighttime clubhouse hours.</li> <li>• Supported housing - safe decent affordable subsidized housing with supportive services.</li> <li>• Involve alumni from jails to come back to help plan and coordinate approaches. Good ways to have people out of jail-have them help make the system better.</li> <li>• Involve lawyers who are interested in civil rights work. Think about test cases as well as setting up legal information and assistance around Olmstead situations.</li> <li>• Looking at the broader scope of mental illness and see how it effects each unit of the system.</li> <li>• Provide education to both</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
		<ul style="list-style-type: none"> <li>• Consistency in addressing concerns of provider and needs of consumer.</li> <li>• Provide sufficient on going training that focuses on recovery issues.</li> <li>• Look at the difference between mental health and mental illness.</li> <li>• Supportive housing model needs to address issues of mental illness that effect adequate family services.</li> </ul>	<p>consumer and provider that addresses mental illness and mental health</p> <ul style="list-style-type: none"> <li>• Explore programs that exist and see where replications have been made\</li> <li>• Provide outreach workers in housing to assist families with their needs</li> <li>• Involve alumni from jails to come back to help plan and coordinate approaches. Good way to have people out of jail - have them help make the system better.</li> <li>• Involve lawyers who are interested in civil rights work. Think about test cases as well as setting up legal information and assistance around Olmstead situations.</li> </ul>

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**MHT-SIG: Workgroup 2: Mental Health Consumer and Family Driven**

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
<p><b>Protect and Enhance Rights of People with Mental Illness</b></p> <p><u>Rec. 2.5:</u> Protect and enhance the rights of people with mental illnesses.</p>	<ul style="list-style-type: none"> <li>• Fully integrate consumers into their communities under <i>Olmstead</i> decision. Eliminate unnecessary &amp; inappropriate institutionalization.</li> <li>• Eliminate practice of trading custody (forfeit parental rights) for MH care for children with SED.</li> <li>• Eliminate discrimination in employment based on psychiatric diagnosis or mental health treatment.</li> <li>• Reduce use of seclusion &amp; restraint (S&amp;R) in MH treatment settings. Use de-escalation techniques.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of leadership and commitment.</li> <li>• Consumers are not always aware of their rights or are threatened with a loss of service if they try asserting their rights.</li> <li>• Needs to be made available to everyone the rights of people with mental illness.</li> <li>• Lack of prevention services available to schools.</li> <li>• Lack of easily accessed intervention services available.</li> </ul>	<ul style="list-style-type: none"> <li>• Peer advocates should be available to people in all programs.</li> <li>• Peer representation in treatment settings.</li> <li>• Train more peers as staff</li> <li>• Have commissioners make a true commitment.</li> <li>• Develop more community-based services with full access.</li> <li>• Have consumers employed as professionals.</li> <li>• Coordinated media campaign anti stigma.</li> <li>• People who are temporarily incapacitated should be assisted to return to self-determination.</li> <li>• Peer advocacy is needed.</li> <li>• Anti Stigma campaign.</li> <li>• Train Police</li> <li>• School need to be made aware that seclusions and restraint should not be used.</li> <li>• Ensure new programs are fully operational prior to closing old programs (inadequate service maybe better than none at all).</li> </ul>

<b>Recommendation: Goals (Sub-Groups)</b>	<b>Objectives:</b>	<b>Challenges/Issues:</b>	<b>Vision/Strategies:</b>
			<ul style="list-style-type: none"> <li>• Help people to realize the significant contribution of figures like Dick Cavet and Mike Wallace who suffer with mental illness. The more people see that mental illness can effect the lives of some of the most respected people the more likely they are to stop seeing mental illness as a defect or punishment.</li> </ul>
<b>Other:</b>			

Address the Categories across:

- Individual
- Family
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