



## CHAPTER 6

**GOAL 1:** Significantly expand the role of individuals in recovery, and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce.

One of the most profound changes in contemporary health care has been the emergence of the concept of patient-centered care. The IOM (2001), in its seminal report *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*, identified patient-centeredness as one of the six aims for health care improvement. The concept was defined as "...providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions" (IOM, 2001, p. 40). Ironic as it may seem, health care historically has not been patient-centered. Providers and the systems in which they work dominated decision-making processes; individual differences among the persons receiving care were largely ignored, and little information was provided to individuals and their families about illnesses and treatment options.

Individuals and their families are increasingly informed about health and health care. Recipients of services increasingly are bringing information to their providers, asking for information, and insisting on having a greater role in decisions about their care. While progress has been made on this front, the ideal of an individual and family fully informed and actively involved in decision making still occurs far too infrequently (IOM, 2001).

### **Evolving Roles in Mental Health and Addictions**

Significant historical differences have existed between the mental health and addiction sectors regarding the roles of individuals and families. Treatment interventions for persons with substance use disorders carried a tradition of nonmedically driven approaches in which the client has been expected to assume significant responsibility for his or her recovery, and persons in recovery largely staffed treatment programs. In sharp contrast, the mental health field historically has centered on the medical model in its approach, emphasized the expertise and influence of a professional workforce, and considered

consumers and their families as recipients of the care or treatment selected by professionals. While these historical differences are important, there is evidence of convergence toward an approach in which the contributions of professionals and of persons in recovery and their families are simultaneously valued and emphasized. In the addictions sector, there is a growing emphasis on evidence-based practice, competencies, and the development of a professional workforce to deliver care, while also retaining and valuing the contribution of persons in recovery as members of the workforce. In mental health, a forceful consumer movement has been a counterbalance to the autonomy and independence of professionals; the consumer movement has emphasized consumer roles in treatment decisions as peer volunteers, as paid employees in the workforce, and as members of the governing boards of provider organizations and service systems. Simultaneously, families have made their voices heard as they have demanded information, influence in treatment decisions, and greater access to care, quality of care, and safety of services provided.

Senior advisors to the Annapolis Coalition grappled with the traditional and divergent ways in the behavioral health field of conceptualizing and describing the therapeutic relationship between persons in recovery and persons providing care. The advisors, hoping to move toward some common ground around the goal of improved care, made every effort to resolve, or at least address, the philosophical and language differences that often divide the field. Success in this effort was substantial, yet clearly only partial. The process revealed a common thread in all sectors and traditions, which is a core respect for the individual and family in need of care, and a desire to strengthen the notion of a partnership between those needing and those providing care. It is a partnership in which caregivers, whatever their training and professional status, have essential knowledge and skills to offer, and in which clients, consumers, or patients bring to the process their self-knowledge, values, and wisdom drawn from the lived experiences of mental and addictive disorders and efforts to achieve recovery.

The language and conceptual difficulties are compounded by the variability in the presentation, course, and severity of mental health and addictions conditions among individuals. For example, there are points in the experience of nearly all severe behavioral health conditions at which the capacity of the individual to fully participate in treatment decisions may be impaired. Thus, differing levels of intervention are required, and each must remain exquisitely sensitive to the dignity and personhood of the recovering individual.

The role of families also is complicated. Family members of children and young adults never lose their role as parent or sibling, and yet they are in a very real sense both primary caregivers and individuals in need of support to sustain their own health and well-being. For adults with mental health conditions, the

situation is even more complex because the family's role in treatment may be limited by the desires or needs of the client.

## **Persons in Recovery and their Families as Members of the Workforce**

From the perspective of workforce planning and development, priority attention must be given to the fact that persons in recovery and their families have an enormous role in caring for themselves and each other. The amount of services provided by behavioral health professionals and other health and human service providers pales in comparison to the amount of self-care, peer support, and family caregiving that is rendered continuously. Individuals with mental health and addiction problems, along with their families, are a human resource that has been too often overlooked or underutilized. A core strategic goal must be to recognize persons in recovery and their families as part of the workforce and to develop their capacity to care for themselves and each other effectively, just as attempts are made to strengthen the professional workforce.

Goal 1 in this Action Plan is to greatly expand the role of persons in recovery and families as part of the workforce. Five major objectives have been identified to achieve this goal, each of which is discussed in the sections that follow. The first objective is to create fully informed individuals and family members by providing better educational supports. Shared decision-making is a second objective, to be accomplished by training individuals, families, and their providers in collaborative approaches to care. Two additional objectives focus on formal roles in the workforce for persons in recovery and family members through expanded peer- and family-support services and increased employment of these individuals as paid staff in prevention and treatment systems. A final objective, engaging persons in recovery and family members as educators of the workforce, is designed to shape the education of providers and, again, foster more collaborative relationships between the people receiving and providing care.

### **Objective 1: Provide information and education to individuals in care or recovery and their families to enable them to fully participate in or direct their own care and to assist and support each other.**

There have been notable efforts to provide information and education to persons in recovery and family members. Examples in the area of substance use disorders treatment include the long-standing work of the Hazelden Foundation and the Johnson Institute. In mental health, the recent work of organizations such as the National Alliance on Mental Illness (NAMI), Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD), and the Depression and Bipolar Support Alliance (DBSA) to educate clients or consumers and family members is particularly noteworthy.

Despite these efforts, there is a general consensus that most individuals and family members with behavioral health needs lack adequate and timely information about illness and treatment options. Much of the information available is not considered user friendly. Furthermore, just as in professional education, there is a serious lag in making the findings or implications of recent studies available to those seeking help. Providing accurate and scientifically sound information to persons in recovery and family members is a core objective and an essential step in supporting their efforts to care for themselves and each other.

A requisite action step is to create mechanisms for developing or updating educational materials that are peer reviewed, scientifically sound, and tailored to individuals of diverse cultures, languages, and points across the life span. Parents also warrant special attention; they require unique information and education because of their evolving roles and needs as their children develop and transition to adulthood.

Several action steps are recommended to make educational materials accessible. They include using multiple media formats and creating a central clearinghouse from which individuals can directly access current information or link to sources of reliable educational materials. This action should be complemented by a searchable database of recent research findings that presents information in layman's language. Public and private health care payers should ensure that persons covered through health plans are provided with links to readily accessible information. State behavioral health agencies each should have an explicit system or structure for educating the public, including individuals receiving state-supported services.

Providers should be trained in communication skills with individuals and their family members, including the art of providing information. In large part, this training should be delivered by persons in recovery or family members, who are uniquely qualified to educate the workforce about the needs and perspectives of the individuals who will be receiving the information. All approaches to disseminating information must address issues of timing and need for repetition. A frequently heard complaint among persons in recovery and their families is that information is typically offered once, if at all, or in a cursory manner during a crisis, when neither the person in recovery nor a family member is likely to retain the information, however useful.

## **Objective 2: Develop shared decision-making skills among individuals receiving care and their families and service providers.**

Education provides a foundation from which persons in recovery and their families are better prepared to exert more influence over their care. Evidence-based practice, as developed in general medicine, places a heavy emphasis on provider and patient collaboration in treatment decisions, informed by the best available and most relevant information for that individual (Guyatt & Rennie, 2002; Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). This concept of shared decision-making has been emerging as a model in multiple areas of health care (Charles & Demaio, 1993), including prevention (Sheridan, Harris, & Woolf, 2003), the treatment of persons with cancer (Cassileth, Zupkis, Sutton-Smith, & March, 1980), and diabetes care (Greenfield, Kaplan, Ware, Yano, & Frank, 1988).

The term *shared decision-making* has not been widely used in behavioral health (Hamann, Leucht, & Kissling, 2003), but it has roots in the field, embedded in efforts to assess client preferences, provide client-centered care, and implement self-directed care (Adams & Drake, 2006). The Annapolis Coalition recommends that efforts be expanded to further develop and widely disseminate this approach in the behavioral health field. This would entail adopting promising practices from other areas of health care and building on emerging models within the field, such as illness management and recovery (Mueser et al., 2002; Mueser et al., 2006) and person-centered (or family-focused and youth-guided) treatment planning (Adams & Grieder, 2004).

Increased adoption of these collaborative approaches will require training targeted not only to providers but also to persons in recovery and family members. Provider-focused trainings will target skills related to communication, building a therapeutic alliance, and eliciting and responding to questions and concerns of individuals and their families; client-focused interventions will facilitate the sharing of opinions and concerns (Adams & Drake, 2006). In addition to these skills-development approaches, the Coalition recommends attention to a range of documentation requirements, accreditation and licensing standards, and reimbursement practices that could be modified or adopted as action steps to support and reinforce shared decision-making practices.

Shared decision-making approaches are intimately related to issues regarding engagement in treatment (Adams & Drake, 2006). The substance use disorders community has focused successfully on the engagement issue by developing strategies such as motivational interviewing (Bernstein et al., 2005; DeJonge, Schippers, & Schaap, 2005; Hettema, Steele, & Miller, 2005). These strategies should be incorporated more broadly into provider training and skills development.

### **Objective 3: Significantly expand peer- and family-support services and routinely offer them in systems of care.**

The role of peer supports and self-help has been at the foundation of substance use disorders treatment for decades. In mental health, formal peer- and family-support programs have a more recent history, yet there has been substantial growth in these approaches over the past decade. Fostering a strong and expanded role for persons in recovery and family members in formally helping their peers is a core workforce objective.

For the adult mental health community, this objective has special meaning; the emergence of peer supports as a Medicaid reimbursable service has become a major theme in system reform. There is an emerging body of evidence supporting peer services for persons with serious mental illnesses (Campbell & Leaver, 2003; Sabin & Daniels, 2003; Solomon & Draine, 2001). The evidence from implementing Medicaid reimbursable services in state systems such as Georgia and South Carolina adds support to the movement. It is recommended that all states pursue implementation of Medicaid reimbursable peer support. To foster this development, the federal Centers for Medicare and Medicaid Services (CMS) should work with its regional officers, states should develop relevant regulations for their Medicaid plans, and work must continue on identifying competencies and developing a curriculum for peer specialists.

On a parallel track, systems need to devise strategies to support the expanded use of volunteers, whenever possible. The 12-step and other mutual aid communities have values and traditions that mandate voluntary service, and many persons in recovery and family members are not interested in paid positions within systems of care. Their contributions cannot be slighted, or worse, thwarted by policies or practices that ensue from efforts to expand peer-support programs tied to Medicaid.

It is essential that family support initiatives, such as the Family to Family program developed by NAMI, be substantially expanded. Training in peer- and family-support models should be routinely available in all provider settings. Furthermore, these approaches to providing support must be adapted to the unique needs of individuals of color, non-English-speaking populations, and residents of rural communities. Finally, a more robust research and evaluation agenda should be mounted to ensure that emerging and promising practices in peer and family support receive adequate focus in the nation's effort to identify, develop, and fund evidence-based practices.

Though addressed elsewhere in this document, it is important to note that participants in the planning process called for all persons in recovery, family members, *and* providers to receive support. The

repeated message was that recovery can be stressful and demanding, regardless of one's role in the process. The benefits of peer support are not limited to individuals with a diagnosis or disorder.

**Objective 4: Increase the employment of individuals in recovery and family members as paid staff in provider organizations.**

The substance use disorders treatment community has far outstripped the rest of behavioral health in employing persons in recovery. However, all sectors of the behavioral health field have work to do to ensure that people in recovery are provided opportunities to enter the paid workforce, not only in positions identified as peer-support roles, but in standard or traditional workforce positions as well. A special challenge is to provide meaningful career ladders for people in recovery, so that they can not only enter but also remain in the field and continue to grow personally and professionally. Individuals in recovery and family members should hold supervisory and management positions within prevention and treatment organizations, in addition to the frontline, direct care positions for which they are so often recruited.

The realities of achieving increased employment of persons in recovery and family members are complex and will require creativity and flexibility in dealing with issues such as the education and licensure requirements for selected positions, as well as workforce-related provider accreditation standards. It will also require the creation of reimbursement policies that go beyond academic preparation and licensure as eligibility requirements for compensation. There is a strong need to recognize and pay for the services of individuals who bring life experience as a qualification and have demonstrated their competency in nontraditional ways.

To monitor and drive progress on this objective, all provider organizations, systems of care, and state behavioral health agencies should formally monitor the number and percentage of self-identified persons in recovery and family members that they directly employ or fund through contracts. Specific targets should be set on this objective within each organization and pursued through a comprehensive plan to recruit and orient peer and family employees, and most critically, to support individuals once they are engaged in these roles.

**Objective 5: Formally engage persons in recovery and family members in substantive roles as educators for other members of the workforce in every provider training and education program.**

One of the largest gaps in the field is the absence of individuals in recovery and their families as teachers of the traditional workforce about the experience of illness and treatment and the process of recovery.

These rich perspectives from lived experience are undervalued and are seldom provided in traditional academic preparation or continuing education. The conversation changes profoundly when people in recovery and their families are included as faculty in workshops or academic course work. Such inclusion, particularly in early phases of training, has the potential to foster a sense of partnership and collaboration, and to counter the paternalist attitudes and approaches that are taught in traditional academic curricula. This is less of an issue in substance use disorders training, given the historical engagement of persons in recovery as treatment providers. Yet, there is room to expand the role of these individuals as teachers.

A number of concrete strategies can further this objective. First, the educational accreditation bodies of the traditional behavioral health disciplines should endorse inclusion of individuals in recovery and family members on the faculties of their professional training programs and monitor the extent to which this actually occurs in a meaningful fashion. The leaders of state and county mental health and addiction systems can mandate that all trainings<sup>2</sup> paid for with state or county funds include presentations by members of the recovery community and their families. At the federal level, participation of persons in recovery and families could be required in the design, delivery, and evaluation of all federally sponsored training related to behavioral health. Similarly, organizations that accredit continuing education could require that selected course offerings be designed so as to include consumer and family educators.

## **Conclusion**

Inherent in the concept of transforming the mental health system, as the New Freedom Commission on Mental Health called for in 2003, is a shift in power. Emerging approaches to care in behavioral health involve shifts in the locus of decision making and forming more equal partnerships between persons in recovery and family members, and providers. Many individuals who participated in the development of the Action Plan considered this strategic goal, focused as it is on an expanded role for persons in recovery and family members, to have the greatest potential to transform systems of care, especially within mental health. Persons in recovery and family members too often are unrecognized as members of the workforce. They currently make enormous contributions caring for themselves and each other, but they can have even greater impact if provided with information, skills in shared decision-making, opportunities to provide formal peer and family support, and a role in educating the traditional workforce. Given what appears to be an insurmountable gap between the demand for and supply of traditional providers, engaging individuals with the most at stake in roles that are more meaningful and effective

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<sup>2</sup> There would be obvious exceptions for technical or organizational training matters or the use of content-specific instructors (e.g., epidemiologists, pharmacists, etc.).

provides the additional hope of reaching many individuals who have not connected with traditional systems of care.

Just as persons in recovery and family members are unrecognized members of the workforce, so too are communities. The role of communities in the workforce, a second potentially transformational strategic goal, is addressed in the following chapter.

### Table 6.1: Objectives & Actions for Goal 1

**GOAL 1: Significantly expand the role of individuals in recovery, and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce.**

**Objective 1: Provide information and education to individuals in care or recovery and their families to enable them to fully participate in or direct their own care and to assist and support each other.**

Action 1: Identify and make available to people in care and their families a body of peer-reviewed, scientifically sound, culturally and linguistically relevant materials in a variety of formats (text, video) and languages, and make these materials accessible to people with different educational levels.

Action 2: Routinely provide families and other natural caregivers and supporters information about optimal ways to help and support loved ones with behavioral health conditions; this information is developed and provided by consumers, family members, educators, researchers, and providers working in partnership(s) and reflects the range of cultural and linguistic differences of the country.

Action 3: Routinely engage persons in recovery and family members in teaching providers how best to work with persons seeking recovery from the perspective of the lived experience of mental or substance use conditions.

**Objective 2: Develop shared decision-making skills among individuals receiving care and their families and service providers.**

Action 1: Expand the knowledge base about shared decision-making.

Action 2: Make person-centered (or family-focused or youth-guided) treatment planning the norm in behavioral health interventions.

Action 3: Make consumer, family, and provider education a part of every provider interaction – no matter how often the provider has seen the consumer or family.

**Objective 3: Significantly expand peer- and family- support services and routinely offer them in systems of care.**

Action 1: Implement certified peer specialist (CPS) services as Medicaid reimbursable in all states by 2010.

Action 2: Expand the use of volunteer and grant-funded peer-support programs where indicated.

Action 3: Expand family support services (such as the NAMI Family to Family program and similar programs) in all provider settings, and adapt these programs to meet the needs of diverse communities (based on race, class, sexual orientation, geographic isolation, and language).

Action 4: Continue to build the evidence base on peer-support practices.

Action 5: Create opportunities for providers to support each other emotionally. (The emotional demands of their jobs are intense, and support among providers would be an excellent way to build resilience.)

**Objective 4: Increase the employment of individuals in recovery and family members as paid staff in provider organizations.**

Action 1: Develop mandates and standardized reporting mechanisms for self-identified consumers and family members employed as providers in non-peer-support positions, as well as in peer-support positions.

Action 2: Advocate for CMS endorsement of the use of appropriately trained individuals in recovery or family members as providers under state Medicaid plans.

**Objective 5: Formally engage persons in recovery and family members in substantive roles as educators for other members of the workforce in every provider training and education program.**

Action 1: Propose that national oversight bodies for each of the major behavioral health disciplines endorse inclusion of individuals in recovery and family members on the faculties of their pre-professional training programs.

Action 2: Propose that national educational oversight organizations that accredit residencies and practica endorse the use of individuals in recovery and family members as preceptors or consultants to preceptors.

Action 3: Include individuals in recovery and family members in the design, oversight, delivery, and evaluation of all state-sponsored training.

Action 4: Include individuals in recovery and family members in the design, oversight, delivery, and evaluation of all federally sponsored training.

Action 5: Include a course led by consumers and family members regarding recovery from the consumer and family member perspective in all provider-sponsored continuing education programs.

Action 6: Encourage providers, states, and organizations to use teams of consumers and providers to offer continuing education.

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