

“Patient-Centered” and “Consumer-Directed” Mental Health Services*

By

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Introduction

The purpose of this report is to examine the concept of “patient-centered” health care, as elaborated in the Institute of Medicine’s (IOM) *Crossing the Quality Chasm* report, and how it is manifested in the delivery of mental health services in the United States. This will involve a review of service delivery models and evidence of their effectiveness from a number of fields of study including self-determination, self-directed care, and an array of mental health programs and services that exemplify consumer-directed care, including self-help/mutual aid support groups, illness self-management, psychiatric advance directives, seclusion and restraint reduction strategies, consumer operated programs, consumer staff working in traditional mental health settings, and others. Also considered will be the extent to which mental health care today is “patient-centered,” as defined in the *Quality Chasm* report, and the therapeutic importance of it being so to behavioral health theory, research and practice.

Patient-Centered Care

As discussed in the IOM’s *Crossing the Quality Chasm Report* (2001), there are multiple dimensions of patient-centered care (Gerteis et al., 1993) including respecting patients’ values, beliefs, and preferences; customizing care to the individual and making sure that care is culturally competent; and recognizing that patients’ preferences may change over time and in response to shifts in clinical and other circumstances. Patient-centered care involves coordination and integration of care, ensuring continuity from one setting to another, and exchange of information in a timely and accurate fashion. It also requires effective communication and education of patients, including provision of accurate and understandable information about a patient’s diagnosis, prognosis, and treatment options, delivered in a fashion tailored to patients’ communication preferences. Patient-centered care focuses on ensuring the patient’s physical comfort through expert management of symptoms so that individuals are as free from pain and suffering as possible. This includes providing emotional support to patients, with the intent of lessening their fear and anxiety by attending to their experiences of uncertainty, loneliness, disability, and the negative financial impact of illness. Patient-centered care accommodates the patient’s family and friends, by involving them in decision-making and caregiving, recognizing their needs and potential contributions, and welcoming them in the care environment, to the extent desired by the patient. The accomplishment of these objectives involves healing relationships in which high quality technical skills and sensitive interpersonal interactions occur in a manner tailored to each patient’s preferences regarding their desired degree of involvement in decision-making. Ultimately, patient-centeredness requires customization of care so that it meets the person’s needs rather than vice versa.

Moreover, the IOM *Quality Chasm* report identifies ten rules for accomplishing each of its six aims for improving healthcare quality, of which patient centeredness is one. The third of these ten rules identifies “the patient as the source of control,” defined

as giving patients, "...the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making" (2001, p. 61).

In a follow-up to its *Quality Chasm* report, the IOM's *Priority Areas for National Action: Transforming Health Care Quality* report (2003) identified Self-Management and Health Literacy as key to instituting patient-centered care. Self-management is defined as the systematic delivery of information and supportive activities to enhance the skills and confidence of patients in managing their own illnesses. This includes ongoing assessment of progress and impediments, goal setting, and assistance with problem solving. Successful self-management programs have been found to include: 1) provider reinforcement of patients' primary and active role in managing their illnesses; 2) use of standardized assessments by provider teams; 3) use of evidence-based practices in care delivery, and 4) an individualized care plan for every patient developed through collaborative discussion and focused on patient-centered problem solving (Glasgow et al., 2002).

Given the primacy of patients and their caregivers in managing chronic illness, health education is required for successful health outcomes and educational efforts must take account of low literacy levels among substantial proportions of the American population. The *Transforming Health Care Quality* report notes, for example, the finding that 46% of U.S adults are estimated to be functionally illiterate in healthcare matters (American Medical Association, 2002) and that recall of medical instructions and understanding of prescription medication directions is extremely poor (Pfizer, 1998). At the same time, however, factors beyond simple knowledge, such as motivation and positive attitudes, are required for successful management of chronic disease. Self-management efficacy is enhanced when medical information is accompanied by plans tailored to individual patients, regular patient self-monitoring, and provider review (Gibson et al., 2002). In addition, medical information is more effectively imparted via multiple methods such as written, verbal, and pictorial/visual representations, and with sensitivity to the extra difficulties experienced by elderly and low-income populations.

The concept of patient-centered care has its roots in U.S. case law (Lambert, Street, Cegala et al., 1997) that has held since 1906 that patient consent is required for medical treatment (Pratt vs. David, 1906), and since 1956 that appropriate information is required for informed consent (Salgo vs. The Leeland Stanford Hospital Board of Trustees, 1956). Writing in 1997, Lambert and colleagues noted that increasing attention was being devoted to this area and reported on their search of the Medline database for published articles with the phrase "patient-centered" in the title. This search yielded 4 such articles between 1975 and 1979, 10 between 1980 and 1984, 12 between 1985 and 1989, and 34 between 1990 and 1996. The present author's recent search of the final six year interval revealed a total of 197 articles with the phrase "patient centered" in the title between 1997 and 2004, showing that interest in patient-centered care has continued to grow.

Self-Determination Theory and its Relevance to Patient-Centered Care

The concept of patient-centered care is better understood in relation to the notion of human self-determination. Self-determination theory (SDT) has been developed over the past three decades based on the findings of psychological research done by Edward L. Deci, Richard M. Ryan and their collaborators (Deci & Ryan, 1985; Ryan & Deci, 2000). SDT is a metatheory of human motivation concerned with the workings of individuals' innate inner resources for personality development and behavioral regulation and how these are influenced by social contexts (Ryan & Deci, 2000). SDT focuses on the degree to which human behaviors are volitional, that is, the degree to which people endorse their actions at the highest level of reflection and engage in these actions with a full sense of choice (Russell, Cook et al., 2004). SDT research has used traditional empirical methods (e.g. randomized experiments, mathematical modeling of longitudinal survey data) to establish the central importance to self-determination of three innate psychological needs: self-perceived competence, autonomy, and relatedness. SDT research has shown that people must perceive themselves as competent and experience their behavior as volitional in order for intrinsic motivation to be present. For activities not intrinsically motivated (i.e., not performed for the inherent satisfaction of the activity itself), individuals internalize behavioral regulations by aligning them with their pre-existing values and needs. The critical process of internalization is more likely in the context of feelings of relatedness to others and of autonomy (here, defined not as independence or separateness but instead as the degree of volition with which an act is performed). SDT researchers have repeatedly demonstrated the connection between internalization and more positive health and mental health outcomes. Greater internalization is associated with medication adherence among the chronically ill (Williams, Rodin, Ryan et al., 1998), positive changes in glucose control among diabetics (Williams, Freedman, & Deci, 1998), ability to maintain weight loss among the morbidly obese (Williams et al., 1996), and higher involvement and attendance in substance abuse treatment programs (Ryan, Plant & O'Malley, 1995). These and other studies have demonstrated the relevance of SDT to the fields of medical and mental health treatment, given the importance of motivation in producing lasting behavioral change (Ryan & Deci, 2000).

Communication Theory and its Relevance to Patient-Centered Care

Working from a framework of communication theory, Lambert and colleagues (1997) emphasize that health is more than a biomedical construct, instead, health is a process created and sustained in social interaction. In their analysis, the authors show that health is a temporally emergent construct encompassing a range of processes such as preventing illness, becoming ill, regaining health, and maintaining health. In this theoretical perspective, patient-centered care involves acknowledging and understanding how biological and psychosocial processes interact to affect an individual's health.

At the center of these authors' argument is the notion that health consists of the individual's attempts to align identity, interpretations, and performances. Here, health

is maintained through an ongoing process of interactive stabilization such that “communication is at the very core of what it means to healthy” (Lambert, Street, Cegala et al., 1997, p.32). The example is given of a middle-aged man who perceives himself as healthy and normal, believing that he should engage in an active sexual relationship with his wife. This is his interpretive account or theory of how his identity must be realized in interaction. If he does indeed have an active sex life with his wife this is his performance in the material world. If he is diagnosed with high blood pressure and his prescribed medication causes impotence, this state of impotence becomes a resistance that destabilizes his healthy alignment. His realization that he is impotent leads to a feeling of ill health resulting from the destabilization of alignment between self-image, interpretive account, and performance, with bodily failure as the causal factor. To accommodate to this resistance and regain his health, he may modify any one of his interactively stabilized elements. For example, he might alter his identity to de-emphasize his role as husband and emphasize that of businessman. Or he might change his interpretive account of the meaning of being a good husband, de-emphasizing sexual activity and emphasizing emotional availability. Or he might modify his performance by stopping his high blood pressure medication. Each of these courses of action is fraught with difficulty and uncertainty. It is impossible to know in advance which accommodations will be successful, nor whether some accommodations may lead to new resistances and further destabilization.

Applying this perspective to the study of communication and health suggests that a patient-centered approach to information seeking is one that is attentive to the danger of destabilization (Lambert, Street, Cegala et al., 1997). For example, a great deal of attention in patient-centered care is paid to improving provider-patient communication by enhancing physicians’ communication and relational skills (Kurtz & Silverman, 1996), and improving patients’ question asking behavior (Cegala, 1997). Here, attention to the effects of destabilization might address the patient’s fear of asking stupid questions (threatening one’s identity as a knowledgeable person) or alienating one’s health care provider (thus affecting one’s interpretive account of good patient behavior). Finally, given the socially devalued and negatively appraised role of patienthood in United States society (Goffman, 1961), an interactive approach to health suggests the wisdom of re-conceptualizing patient-centered care as person-centered care, since efforts to maintain health or prevent illness, by definition, lie largely outside the “patient” role.

Both psychological and communication self-determination theory help us better understand the processes underlying patient-centered care. In so doing, they direct our attention to the potential “active ingredients” that should be included in efforts to improve patients’ well-being and medical outcomes. These are important aspects of understanding the efficacy and effectiveness of this form of care, as discussed in the following section.

Self Management of Medical Illnesses: Evidence of its Effectiveness

As mentioned previously, ample evidence exists to support the efficacy of self-management of chronic medical conditions. For example, Lorig and colleagues (1999,

2001) used random assignment to evaluate a chronic disease self management program taught by trained volunteer lay leaders (71% of whom had chronic diseases themselves) that included the following topics: use of medications, dealing with fear, anger and depression; communicating with health professionals; problem solving; decision-making; exercise; nutrition; fatigue and sleep management; cognitive symptom management; and use of community resources. Groups of 10-15 participants of diverse ages and diagnoses (i.e., heart disease, stroke, lung disease, and arthritis) participated in the training over seven weekly 2 and ½ hour sessions. Compared to controls, treatment subjects demonstrated improvements in weekly minutes of exercise, frequency of cognitive symptom management strategies, communication with physicians, and self reported health, reductions in health distress, fatigue, disability, and social limitations, as well as fewer inpatient admissions and days hospitalized. Compared to baseline, at both one and two years post-training, treated subjects reported fewer ER/outpatient visits, reduced health distress, and greater self-efficacy, indicating that disease self-management training effects persisted over time. Similarly, Glasgow and colleagues (1995; 1996; Brown, Glasgow & Toobert, 1996) randomly assigned patients with diabetes to a brief office-based intervention for dietary self-management involving assessment, feedback, goal setting, and support, and found significantly reduced dietary fat intake and serum cholesterol levels among treatment group subjects compared to controls, gains that were maintained at 12 month follow-up. In a review article of self-management clinical trials for arthritis, diabetes, asthma, and mixed chronic illnesses (Bodenheimer, Lorig, Holman et al., 2002) conclude that patient education programs teaching self-management skills produce superior outcomes to programs teaching medical information alone.

Others have noted that chronic disease management is an even broader concept than illness self-management, encompassing an “evaluator role” in which the patient’s perspective is included in performance measurement of healthcare (Hibbard, 2003). This role involves patients in evaluating their experiences of care as well as care outcomes, along with the degree to which they are supported in their “co-producer role” (i.e., responsibility for deciding when to seek care, engaging in self care, providing information critical to making diagnoses, making informed decisions about treatment options, adhering to treatments, and taking preventative actions). Importantly, assumption of the evaluator role may have a synergistic effect on patients’ ability to adopt the medical care “co-producer” and “informed decision-maker” roles. Clearly, the many interconnections between patient-centered care and illness self-management point to the synergy between the two notions.

Consumer Direction of Long Term Care Resources and Self-Determination for People with Disabilities: Evidence of its Effectiveness

Robert Wood Johnson-Funded Self-Determination Programs. In addition to the medical arena, patient-centered care management has penetrated the field of disability. In 1993, the Robert Wood Johnson Foundation’s national program, *Building Health Systems for People with Chronic Illnesses*, evaluated a novel service delivery approach for individuals with developmental disabilities. This approach, pioneered by Monadnock Developmental Systems of Keene, NH, was aimed at 45 individuals and their families.

Individuals were in charge of planning their own support needs in concert with chosen family and friends (referred to as a circle of support). Each person controlled an amount of public money that could be spent on housing, vocational, or personal needs. Individuals could contract directly for all services and supports that were purchased, and they could contract with whomever they chose rather than being limited to entities with which the Monadnock agency contracted. An independent evaluation found that participants reported a significantly improved quality of life along with a cost savings of 12 to 15 percent, regardless of their level of disability (Conroy & Yuskas, 1996). The Monadnock agency expanded its pilot to cover the 500 clients it served and found that it was able to shorten its waiting list, due to the fact that some individuals met their needs by purchasing generic services rather than waiting for a program slot to open up.

In 1995, the Robert Wood Johnson Foundation Board of Directors authorized funding of a national *Self-Determination for People with Developmental Disabilities Program*, intended to give large numbers of individuals and their families greater control over long term care services (Nerney & Shumway, 1996). One- to three-year grants were awarded to 19 states to engage in pilot projects and reforms that involved four key elements. Person-centered planning enabled individuals and their families to learn about available services and choose those that met their specific needs. Independent support brokerage provided assistance to individuals and families to help them locate and arrange needed services and supports. Individual budgets enabled participants to use an allocated pool of money to purchase services and cover other expenditures named in their person-centered plans. Finally, fiscal intermediaries were used to handle all purchasing and accounting functions, deal with employee withholding and other tax related matters, and perform billing services.

A diverse array of projects were conducted as part of this national program, ranging from statewide reform initiatives designed to retool entire systems for self-determination, to smaller pilot programs targeting a small number of individuals and their families as recipients of the four key elements of self-determination. Most states engaged in activities designed to involve self-advocates and their family members in policy development and implementation. All states were able to create a structure, albeit limited in some cases, for delivering services and supports according to the four self-determination principles. States also concentrated on widening the scope of available services to include use of non-traditional, informal supports.

An independent client-level evaluation of the national initiative was hampered by the wide diversity in state programs and the voluntary nature of the data collection effort. A pre-test post-test design was used in which an extensive array of client- and family-level data were collected, at baseline and one to three year follow-up, in a number of domains including autonomy of decision-making, self-care skills, vocational skills, psychological adjustment, stability of living environment, health and health care utilization, social integration, satisfaction, and costs (Conroy, Fullerton, Brown et al., 2002). Participant-level data were collected from 441 individuals located in six states: California, Hawaii, Maryland, Michigan, Ohio, and Wisconsin. The majority of participants were male and, with the exception of Hawaii, Caucasian. Their average ages ranged from a low of 25 years in California to a high of 45 years in Michigan. The

large majority were individuals with mental retardation. In 4 out of 6 states, the majority of participants were purchasing their own services using individual budgets at follow-up, (ranging from a high of 84% with such budgets in Michigan to a low of 56% in Wisconsin). In 3 out of 6 states, there were significant increases in the number of friendships that participants reported at follow-up, and in 2 out of 6 states there were significant increases in participants' productive behavior at follow-up. In 4 out of 5 states (data was not available for the 6th) there were significant increases in a scale measuring the extent to which planning was conducted in a "person-centered manner." Participants in all 6 states showed significant gains on a scale designed to measure changes in degree of consumer decision-making, and participants in all six states showed significant increases in perceived quality of life. In addition, a survey of family members revealed a shift in decision-making from professionals to families and, to a somewhat lesser extent, program participants themselves. On the other hand, clients in some states were significantly worse off on certain outcomes such as social integration, occurrence of productive behavior, and progress toward goals.

A separate systems-level evaluation found that the degree of flexibility in states was associated with successful implementation of individual budgets. In states where systematic approaches to budget development were already in place (e.g., based on costs or an individual's disability characteristics), there was an enhanced ability to make individual resource allocations (Bradley, Agosta, Smith et al., 2001). Also key to success was a system-wide approach, in which state agency leaders transformed entire agencies rather than focusing on self-determination as a "pilot" project. Finally, participants required high levels of support to engage in a person-centered process; thus, states that more effectively implemented self-determination had greater availability of direct support workers and were able to deal with the high degree of turnover in case managers faced with both administrative and support brokerage tasks (Bradley et al., 2001).

Medicaid-Funded Self-Determination Programs. At around the same time as the Robert Wood Johnson Foundation Initiative was drawing to a close, the federal Centers for Medicare and Medicaid Services (CMS) developed a set of services and supports that states could use in conjunction with Medicaid programs to support self-directed care. Self-direction at CMS involves a similar set of four essential elements: person-centered planning, individual budgeting, financial management services, and supports brokerage (Cook, Terrell & Jonikas, 2004). There are several ways that states can apply these essential elements of self-directed care using state and federal Medicaid funding. The 1915(c) waiver is the primary vehicle for self-direction for persons who do not have mental illnesses. The waiver lists a set of Home and Community Based Services including: case management, homemaker services, home health aide services, personal care services, adult day health services, habilitation services, respite services, and other services identified by states and approved by CMS. Under a 1915(c) Independence Plus Waiver, supports brokerage services and financial management services may also be included as Medicaid-reimbursable services. While the 1915(c) waiver is intended for those in nursing home facilities, hospitals, or Intermediate Care Facilities for Mentally Retarded individuals (ICF/MR), the 1915(c) waiver cannot be used to provide home and community based services to adults between the ages of 22 through 64 who would be

served in an institution for mental diseases (IMD), otherwise known as a psychiatric inpatient facility. These individuals are explicitly excluded in federal law [1905(a)(27)(b)], primarily because it has been the historical responsibility of states to provide institutional care to persons with mental illness.

Section 1115 of the Social Security Act allows states to develop experimental, pilot, or demonstration projects by waiving requirements that restrict services and eligibility (Cook, Terrell & Jonikas, 2004). Under a Medicaid program begun in the late 1990s, referred to as Cash and Counseling, states applied for 1115 waivers to enable Medicaid beneficiaries receiving disability-related supportive services in their homes to use a self-directed model of care. Rather than receiving services from professional agencies that arrange and monitor home care, consumers were offered a flexible monthly allowance with which they could purchase disability-related goods and services from whomever they chose, including family and friends. Also provided to participants were counseling and fiscal services for managing their monthly allowances, as well as the ability to designate representatives (such as friends and family members) to act on their behalf.

A randomized evaluation of the Cash and Counseling Program in three states is being funded by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. Thus far, only the results from Arkansas' IndependentChoices program are available. Arkansas designed its program as a voluntary demonstration aimed at individuals eligible for Medicaid-funded personal care services who were 18 years of age or older. Participants were enrolled beginning in December 1998 through April 2001, when the target of 2,000 was met. Potential participants were told what their monthly allowance would be prior to enrollment (allowances averaged \$320 per month), and were asked to name a representative if they wished to do so. They were also required to use agency services if they happened to be assigned to the evaluation's control condition. Following completion of a baseline interview, they were randomly assigned to the experimental or the control condition and followed by the evaluation team. The control condition consisted of usual care delivered through a fee-for-service approach.

Upon assignment to the experimental condition, most Arkansas participants worked with an IndependentChoices counselor who helped them develop a written plan for allowable expenditures. Under this plan they could hire anyone they wanted as providers (except for spouses or representatives) and purchase disability-related goods and services such as home modifications, assistive devices, and supplies. Receipts were required for all expenditures with the exception of incidentals, which could not exceed 10% of total budgets. The large majority of experimental participants used IndependentChoices' fiscal agents to manage employee payroll withholding and other income tax-related functions, write checks on their accounts, and handle other fiscal paperwork.

Evaluation data were collected from 2,008 participants during two computer-assisted telephone interviews at baseline and at follow-up, nine months after randomization (Foster, Brown, Phillips, Schore & Carlson, 2003). An intent-to-treat

methodological design was used so that outcomes measured the effects of having an opportunity to participate in Cash and Counseling rather than actually doing so (i.e., 11% of experimental participants had disenrolled by the time of the follow-up interview and some never developed an approved plan). Participants were predominantly Caucasian, female, and had less than a high school education. Around a third lived alone and two-thirds resided in rural or urban counties with high crime and poor public transportation, characteristic of areas in which paid caregivers are often difficult to find. Many reported being in poor health and experiencing considerable functional impairment. Half of non-elderly and one-third of elderly participants received greater than 12 hours of weekly personal care (the Arkansas maximum allowable without special approval is 16 hours).

Results revealed that experimental participants were more satisfied than controls with the quality of their paid caregivers, particularly with the caregivers' schedules, their reliability, and the way they performed their duties. Experimental group participants were also significantly less likely than controls to report paid caregiver neglect or theft. Experimental group participants also reported fewer unmet needs than controls in areas such as household activities and transportation. Moreover, compared to controls, experimental participants reported reduced likelihood of developing bedsores, having breathing problems, and problems with muscle contractures. There were no differences between treatment conditions in the occurrence of adverse events such as falls or injuries while receiving care. Finally, experimental group participants were much more likely than controls to say they were very satisfied with the way they were spending their lives and much less likely to report being dissatisfied.

In a second report (Dale, Brown, Phillips, Schore & Carlson, 2003) the costs and likelihood of receiving paid and unpaid care were examined. Results revealed that experimental group participants were more likely than controls to receive paid care and less likely to receive unpaid care. Around two-thirds of the experimental participants hired family members as paid caregivers while most others hired friends or acquaintances. In addition, there was a surprising underutilization of paid assistance among control group participants. This low rate of paid care was particularly evident among "new applicant" controls, 51% of whom were receiving no paid care at follow-up compared to only 8% of "new applicant" experimental participants. Experimental group participants were more likely than controls to receive care in evening and other non-business hours. Medicaid expenditures were significantly higher, by \$1,486 per sample member, for the experimental than the control group participants in the first year of the program. This was related to the much lower than authorized amount of care received by control group participants. By the program's second year, however, differences were not statistically significant, due to lower experimental group participant expenditures for long-term care Medicaid services such as nursing facilities and home health care. Thus, Cash and Counseling participants appeared to be substituting personal care services at home for more costly nursing care services, thereby maintaining cost neutrality. In addition, participants who self-directed their own care were more satisfied with the way in which it was delivered, more likely to feel that their needs were being met, and expressed higher life and health satisfaction.

Other Self-Determination Interventions for People with Disabilities. A number of other interventions have been designed to promote self-determination for individuals with disabilities, including both children and adults. Algozzine and his colleagues (2001) identified 51 studies of programs in which one or more components of self-determination were taught to individuals with disabilities. Most interventions focused on teaching and reinforcing choice-making skills for individuals with moderate or severe mental retardation, or teaching self-advocacy techniques to people with learning disabilities or mild mental retardation. Of the 52 programs identified, a little under half (49%) or 24 were aimed at participants over age 21, and only 11.5% included individuals with what was termed “emotional disturbance.”

The authors conducted a meta-analysis of 9 group-based interventions using random assignment or non-equivalent comparison group designs, as well as 13 studies using single-subject (subject as own control) designs. Results regarding the 9 *group-based* studies revealed a median effect size of .60, indicating a moderate gain resulting from the intervention, applying Cohen’s (1988) suggested criteria. These interventions focused primarily on goal setting, individual self-advocacy, choice- and decision-making, and self-awareness. Of these 9 studies, 2 resulted in small effect sizes, 1 a moderate effect, and 6 achieved large effect sizes. Only 16% of effect sizes were negative indicating that less than one-fifth of the interventions produced better outcomes for those not receiving the interventions. A meta-analysis of the 13 *single-subject* interventions showed strong effects for interventions teaching self-determination skills such as self-scheduling, making independent choices during purchasing activities, asking questions, and goal attainment. The median PND (in this case the percentage of non-overlapping data was computed for each intervention and averaged across participants) was 95%, ranging from a low of 64% to a high of 100%. In their conclusion, the authors note that future research on interventions such as these should look for linkages between the skills taught in these programs and concrete changes in the lives of individuals with disabilities such as new opportunities for education, work, and leisure activities.

The foregoing has reviewed evidence for the efficacy of patient-centered care and illness self-management among individuals with chronic illnesses as well as self-direction of care and long-term care resources among those with disabilities. Largely absent from these studies has been a focus on those with mental illnesses or psychiatric disabilities, even though there is little apparent reason for their exclusion. We turn now to a consideration of the parallel system of mutual aid, self-help, and peer support in the field of mental health that has evolved largely outside the system of medical and professional caregiving.

Self-Determination and Patient-Centered Care for Individuals with Severe Mental Illnesses

Self-determination in practice for individuals with mental illnesses refers to their right to have authority and control over their own lives, encompassing concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction (Cook & Jonikas, 2002). In the United States today,

large numbers of individuals with serious mental health problems experience minimal self-determination given society's failure to provide them with evidence-based, recovery-oriented services or choices in how to use available services (Fisher & Ahern, 1999; Lamb, 1994; Manderscheid, Henderson, et al., 1998). In addition, widely acknowledged curtailment of the civil rights of individuals with psychiatric disabilities further limits their degree of self-determination (National Council on Disability, 2000; President's New Freedom Commission on Mental Health, 2003).

These conditions are reflected in the lack of "patient-centered" care in the current U.S. mental health service delivery system. As noted in *Mental Health: A Report of the Surgeon General*, there is continuing debate about causes and effective treatments for most major mental health and substance abuse disorders (U.S. Department of Health and Human Services, 1999). Less than a third of all individuals with diagnosable mental or addictive disorders receive services in a given year (Regier, Narrow, Rae et al., 1993; Kessler, McGonagle, Zhao et al., 1994). Studies show that those who do seek services for both types of disorders receive care that does not meet evidence-based best-practice standards and is often provided in insufficient amounts (Lehman, Steinwachs et al., 1998; Wang, Berglund & Kessler, 2000). The 2003 report of the President's New Freedom Commission on Mental Health noted that, "Currently, adults with serious mental illnesses and parents of children with serious emotional disturbances typically have limited influence over the care they receive or their children receive" and that, "Without choice and the availability of acceptable treatment options, people with mental illnesses are unlikely to engage in treatment or to participate in appropriate and timely interventions" (New Freedom Commission on Mental Health, 2003, p. 29). The extreme fragmentation of the system of care means that many consumers of behavioral health services are overwhelmed and unable to fully participate in their own plans for recovery (ibid.).

At the same time, there are tensions between different mental health and substance abuse treatment stakeholders including representatives of behavioral health systems, trade organizations, clinicians, service users, advocates, family members, politicians, researchers, and others (U.S. Department of Health and Human Services, 1999). These divisions often prevent the degree of multi-stakeholder collaboration necessary to address the many service gaps and fragmentation of care that has resulted from lack of financial resources, inadequate workforce development, dysfunctional mental health, addictions, and disability public policies, and the absence of a national strategy for behavioral health care in the United States today (New Freedom Commission on Mental Health, 2003).

Not surprisingly, the national and worldwide disease burden of mental disorders is considerable. A study commissioned by the World Health Organization (WHO) found that, of the ten leading causes of disability, five were psychiatric conditions such as schizophrenia, substance abuse, and anxiety disorders, with unipolar depression being the leading cause of disability in the world (Murray & Lopez, 1996). In the United States, annual disability costs have doubled in the past ten years to approximately 23 billion dollars per year, while the number of beneficiaries of public disability stipends has increased by 57% from 4 million to 6.3 million citizens (Kouzis & Eaton, 2000).

These burgeoning levels of disability prevalence and costs have attracted the attention of policy makers in the U.S. and elsewhere, generating much research and policy analysis. Given these parameters, the potential public health value of increasing the degree to which the United States mental health and substance abuse treatment systems are “patient-centered” is substantial.

Despite this negative context, the past two decades have seen the development and popularization of the notion of recovery from mental illness. Recovery in this context refers to a process by which individuals re-conceptualize and reconstruct their lives following a diagnosis of major mental illness (Anthony, 1993). It is a process in which people “experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability” (Deegan, 1988). The emphasis of this framework is not on “curing” or eliminating symptoms and impairments altogether, but instead on learning to cope with them in a way that allows the individual a large measure of dignity, maximal self-determination, and the highest level of role functioning possible. Research in this field has identified a set of outcomes that result from the recovery process and a recent literature review (Lieberman, Kopelowicz, Ventura & Gutkind, 2002) suggests that these outcomes are both subjective and objective. Subjective outcomes include the establishment of meaningful relationships and social roles, and the development of a sense of hopefulness and purpose in life. Objective outcomes of recovery from mental disorders include symptom remission, improved or restored vocational functioning, independent living, and economic security.

The promulgation of self-determination and recovery for people with severe mental illnesses is supported by a set of values that operate at individual, societal, and systemic levels. Some individual values of self-determination and recovery include freedom of choice, control over one’s own life, access to support and assistance, and personal responsibility. Societal values include promotion of civil liberties, fairness, freedom from coercion, and nondiscrimination. Systemic values include service efficiency, effectiveness, and quality, along with consumer satisfaction (Cook, Terrell & Jonikas, 2004).

Consistent with the notions of recovery and self-determination, a variety of consumer-directed mental health programs and organizations have developed, joining those already in existence prior to the widespread dissemination of the recovery and self-determination paradigms (Cook & Jonikas, 2002). These include self-help/mutual aid support groups (Galanter, 1988), other consumer-operated programs (Campbell & Salzer, 2002), mental illness self-management (Copeland, 2004), advance directives or “living wills” for mental health care (Sherman, 1998), advance crisis planning to reduce seclusion and restraint in inpatient settings (Jonikas, Cook et al., in press), and consumer service providers working in traditional programs (Jonikas, Solomon, Cook et al., 1997).

In what follows, a brief review will describe each of the models/approaches listed above in terms of their 1) origins, 2) hallmarks, and 3) similarities to and differences from patient-centered care as defined in the IOM Crossing the Quality Chasm report. Following that, the evidence base for these approaches will be examined

in terms of its demonstration of the efficacy of these models, their degree of attendant participant satisfaction, and the ways in which they influence service utilization.

Mental Health Self-Help and Mutual Support Groups. Mental health self-help and mutual support groups take a variety of forms. Examples include face-to-face, telephone conference, or internet-based groups; professionally-run, consumer-run or co-led groups; and groups designed to educate people about the etiology and treatment of mental illnesses, to teach coping skills and illness self management strategies, to provide mutual-aid and support, or some combination of these (Williams & Whitfield, 2001). Self-help most often is used as a complement to professional care, but also can serve as an alternative to formal mental health services, particularly for those ex-patients who are disillusioned with the formal system (Meek, 1994). A nationally representative telephone and mail survey conducted in 1996 (Kessler, Mickelson & Zhao, 1997) found that 5.9% of those without a mental disorder and 18% of those with severe mental illness reported attending a self-help group in the past 12 months. Self-help groups for people with mental illnesses emerged in the 1950s, such as GROW, Recovery, and the Depression and Bipolar Support Alliance (formerly the National Depressive and Manic-Depressive Association), and since then, their use in this field has markedly grown and expanded with the development of new self-help groups such as Double Trouble for people with mental illness and addictions.

Salzer and his colleagues (2002) describe three types of consumer-delivered mental health service programs. The first is consumer-operated service programs, which are planned, managed, and staffed entirely by consumers. The second is consumer partnership service programs, in which consumers deliver services and share control of the program with non-consumers, especially regarding fiscal and administrative functions. The third is consumers as employees in programs which employ consumers and non-consumers alike, but which are managed and administered by non-consumers (Salzer et al., 2002). Peer support and self-help are typically delivered in consumer-operated and consumer partnership arrangements. Since most consumer-run peer support groups are facilitated by volunteers, group leaders seldom provide these services as paid employees of traditional programs, although such programs may “host” a mutual-aid support group on their premises.

In general, mental health self-help groups aim to teach new skills for coping effectively along with methods of self-advocacy, and to encourage situations of mutual acceptance, support, mentorship, and socialization. Self-help groups also shift public and private mental health systems’ reliance from professional to consumer-centered models, while simultaneously working to humanize public policies and societal attitudes about people with mental illnesses (Perry, Davis, & McVeigh, 1993).

Some of the main barriers to self-help as a model to foster person-centered care include deficient knowledge among professionals about such groups in their communities; lack of accessibility of groups for potential members (both geographically and in scheduling); scarcity of transportation, child care or other supports to allow people to attend; insufficient diversity of groups in terms of personal characteristics such as race/ethnicity, gender, and age; and a history of distrust or contention between self-

help members and treatment professionals (Bacon, Condon, Fernsler et al., 2000; Emerick, 1990; Lyons & Root, 2001; National Mental Health Consumers' Self-Help Clearinghouse, 1999; Thomas, 1999; U.S. Department of Health and Human Services, 1999; Wituk, Shepherd, Slavich et al., 2000).

Self-help/mutual-aid support groups incorporate many of the critical elements of patient-centered care such as respecting participants' preferences, effective communication, and provision of emotional support. These services also contain the ingredients of successful illness management approaches such as offering education and supportive activities designed to enhance participants' skills and confidence in managing their illnesses. However, as indicated above, they often exist independent from the patient's clinical mental health, substance use, or general medical care providers, in cases where such providers are operating, presenting the need for strong coordination and communication mechanisms. Another significant feature is that this approach to mental health care typically de-emphasizes the direct participation of professionals who are acting in a clinical capacity.

Peer-Based Addiction Recovery Support Services. As described by White (2004), the history of Addiction recovery mutual aid societies and peer-based social support is a long and rich tradition stretching from 18th century to the present and encompassing Native American "recovery circles," fraternal temperance societies, and social support provided within inebriate homes and asylums, half-way houses, and self-managed recovery homes. White has provided an excellent overview of the origin, rationale, issues, risks and benefits, obstacles, and recommendations regarding peer-based addiction recovery support services (2004). In what follows, his ideas are briefly summarized. The interested reader is directed to his recent overview (White, 2004) and to a summary of the relevant issues currently facing the field of alcohol and other drug (AOD) treatment (White, Boyle & Loveland, 2002).

As conceptualized by White and his colleagues (2002), addiction recovery management models include four essential elements: 1) sustained monitoring of recovery including recovery checks; 2) stage-appropriate recovery education; 3) active linkage to "indigenous" communities of recovery; and 4) early re-intervention to prevent relapse and sustain recovery. Peer-based addiction recovery is built on the premise that recovery begins prior to the cessation of substance use and requires "recovery capital" that can be enhanced through support services. Moreover, the forces that stimulate the initiation of recovery are different from the forces that affect its maintenance. Both positive (hope) and negative (pain) forces are seen as driving the recovery process and peer-based recovery support services influence the former. The recovery trajectory is assumed to be a lengthy one, with full stabilization occurring at 4-5 years. Finally, long-term recovery is mediated by the availability of social support.

As with mental health peer-support and mutual aid, the rationale for peer-based recovery support services is that individuals in recovery have special sensitivities, enabling them to offer their peers a unique "insider" perspective. As such, they can provide the services of a "personal guide" to assist those attempting to disengage from cultures of addiction. Peer-based recovery support moves the locus of treatment from

institutions and programs to individual's natural environments. It serves as a link to existing sobriety-based support groups but does not seek to supplant them. Through the establishment of reciprocal and enduring relationships, peer-based recovery support can be provided in a number of service settings: clinical or community, acute treatment versus long-term recovery management, existing addiction treatment programs, community organizations, or recovery-specific organizations. Finally, peer-based addiction recovery services are always adjunctive to professional treatment as well as sobriety-based support group models.

Consumer Operated Mental Health Programs. As mentioned above, consumer-operated service programs (COSPs) are designed, managed, and staffed solely by individuals in recovery. In addition to peer support and self-help groups described above, COSPs include drop-in centers, vocational rehabilitation programs, clubhouses, and peer-to-peer programs. One example of a COSP is the state of Georgia's Certified Peer Specialist (CPS) Program (Sabin & Daniels, 2003). To qualify for certification as a provider, CPSs must openly identify themselves as current or former recipients of mental health treatment, and demonstrate past advocacy or advisory experience, as well as a history of successfully self-directing their own mental health recovery. In order to become certified, peers participate in a two-week training course covering topics such as ethics, confidentiality, service documentation, and specific activities designed to develop skills for mental health recovery (Sabin & Daniels, 2003; Fricks & Tiegreen, 2004). Some of these skills include self-management of mental illness, independent activities of daily living, goal setting and problem solving, self-advocacy, employment readiness, and identification and use of natural supports (Fricks & Tiegreen, 2004). Peer specialists also are required to serve as role models, advocates, and change agents in the development of state mental health policies. At the end of the training course, peers must pass both oral and written examinations for certification.

The Georgia program is especially innovative because the services of CPSs are Medicaid reimbursable under the state's rehab option. To maintain the model's integrity, the state requires that peer supports be delivered only by CPSs employed by consumer-operated programs. To date, two other states (Iowa in 2003 and South Carolina in 2004) have adapted this certified peer specialist program, and received approval to implement the new services (Tiegreen & Fricks, 2004). It bears noting that, to use the Medicaid rehabilitation option in this way, a State must ensure adequate training, care coordination, supervision, and ongoing support of its peer specialists (Cook, Terrell, & Jonikas, 2004).

The hallmark of consumer-operated programs is the large extent to which services are tailored to the recovery needs of participants, much like patient-centered care. This model also provides skills training in consumers' chosen goal areas, consistent with the central thrust of self-determination in setting and achieving person-centered plans. As with mutual-aid and self-help support groups, consumer-operated programs de-emphasize or actively prohibit the participation of clinical professionals acting in their professional roles.

Consumer Service Providers in Traditional Programs. As interest in self-help

and recovery has grown over the past twenty-five years, so has the employment of people with serious mental illnesses as providers of traditional mental health and rehabilitation services (Moxley & Mowbray, 1997). By the 1980s and 1990s, federal agencies such as the Substance Abuse and Mental Health Service Administration's (SAMHSA) Center for Mental Health Services (CMHS), the U.S. Department of Education, and the Office of the Surgeon General were endorsing this type of consumer involvement, as were professional associations such as the National Association of State Mental Health Program Directors and the International Association of Psychosocial Rehabilitation Services.

One important assumption underlying this trend is recognition that the development of knowledge and skills needed to help people with mental illnesses recover can come from sources other than professional training (Salzer & Mental Health Association of Southeastern Pennsylvania Best Practices Team, 2002). An additional tenet is that consumer staff bring something unique and valuable to the treatment process: a personal understanding of what it is like to cope with the symptoms and social effects of these types of illnesses (Solomon, Jonikas, Cook, & Kerouac, 1998).

Within traditional programs, people with mental illnesses hold a variety of paid positions including case manager (Chinman, Rosenheck et al, 2000), peer specialist (Felton, Stastny, Shern et al., 1995), crisis worker (Lyons, Cook, Ruth et al., 1996), job coach (Mowbray, Rusilowski-Clover, Arnold et al., 1994), supported education tutor (Cook & Solomon, 1993), team leader (Solomon & Draine, 1995), and residential manager. These positions range from those that are unpaid, to those that are paid but created or "set aside," (available only to people with mental illnesses), to those that are paid and competitive (available to consumers and non-consumers) (Curtis, 1993).

Use of consumers to deliver mental health services in traditional settings demonstrates that people with mental illnesses can recover as well as contribute to the recovery process of others. Further, because consumer providers draw from personal experience, they tend to develop a strong sense of identification with their clients, and are more likely to view them holistically, as individuals with a variety of mental health and non-mental health needs (Nikkel, Smith, & Edwards, 1992). Also, because they have first-hand experience with the deficiencies of public and private systems, they often are more adept than their non-diagnosed counterparts in developing a range of creative options to address the needs and preferences of their clients (Solomon et al., 1998).

Some of the barriers to hiring consumers in traditional mental health programs include discriminatory attitudes about people with mental illnesses sometimes found among the non-consumer workforce, internalized stereotypes among consumers themselves about their abilities to provide services or to receive them from other consumers, deficient knowledge among program administrators about how to hire and adequately support consumer providers, and lack of Medicaid-reimbursement for peer-delivered services in most States (Solomon et al., 1998).

The peers as employees model in mental health contains many of the same features as self-directed care for individuals with medical conditions. Here, peers can

act as professional providers by combining high quality technical skills with a unique sensitivity to interpersonal interactions. Peer providers' own personal experiences with the service delivery system may enable a degree of customization of care that is difficult for non-consumers to achieve. The role modeling opportunities of this model also have the potential to build client confidence and hopefulness in ways that professional providers cannot accomplish.

Mental Illness Self-Management. Although the concept of recovery from mental illness is relatively new (Deegan, 1988), people with this illness have been self-managing and functioning in the community long before the idea of recovery became popularized (Harding, Brooks, Ashikaga, Strauss, & Breier, 1987). People with psychiatric diagnoses have countless ways of "getting on with their lives" (Allott, Loganathan, & Fulford, 2002), which have begun to be documented and formalized over the past two decades.

Studies show that self-management -- or a person's determination to get better, manage the illness, take action, face problems, and make choices -- facilitates recovery from mental illnesses (Allott et al., 2002). Self-managed care strategies are as varied as people themselves, but some common techniques include: writing down or talking about problems, contacting or visiting with friends, exercising, praying/meditating, creative endeavors, practicing good nutrition, and engaging in self-advocacy (Rogers & Rogers, 2004). For many, voluntarily taking psychotropic medications and using formal services are aspects of self-managed care as well. In fact, it can be argued that self-management of psychiatric illnesses is at the heart of consumer-directed mental health treatment.

Several manualized self-management programs have been developed in recent years, two of which are Wellness Recovery Action Planning (Copeland 1997) and Taking Charge (VanSickle 1996). Copeland's Wellness Recovery Action Planning (WRAP) is a program for identifying internal and external resources for facilitating recovery, and then using these tools to create a plan for successful living (Copeland 1997). Creating a WRAP plan generally begins with development of a personal Wellness Toolbox, consisting of simple, safe, and (usually) free self-management strategies mentioned previously such as a healthy diet, exercise, sleep patterns, and pursuit of adult life roles (Copeland 2004). The person then uses this Toolbox to create an individualized plan for using each strategy to obtain and/or maintain recovery. The plan also includes identification of "early warning signs" of symptom exacerbations or crisis, and how the Toolbox can help people to manage and feel better. WRAP also encourages development of a crisis plan, which states how the person would like to be treated in times of crisis (similar to an advance directive, discussed elsewhere in this report), as well as a post-crisis plan for getting back on the road to recovery.

VanSickle's Taking Charge program, based on the self-help tenets of Recovery, Inc., teaches people with mental health difficulties personal management skills to improve their outlook on life and chances for success (VanSickle 1996). Like most self-management approaches, it also has wellness, rather than illness, as its foundation. The program uses strategies similar to cognitive skills training and cognitive behavior therapy to help people identify thoughts and impulses that create ill health and distress,

and how to control them for a healthier, happier life. Individuals with emotional or mental disorders are shown how to examine their reactions to daily events at the most basic levels, and use simple cognitive “reframing” tools to regain control over their responses and attitudes towards life.

Since mental illness self-management programs lie at the heart of consumer-directed care, it is not surprising that they are highly similar to patient-centered care in their philosophy and intended outcomes. The goal of both types of programs is health-related behavior change, with attention to acquiring new information and skills to better manage troublesome symptoms and maintain higher levels of health and functioning. The reliance on structured techniques and strategies for managing illness and ongoing self-assessment and self-monitoring are also considered active ingredients in both approaches.

Advance Directives for Mental Health Care. Advance directives for mental health care consist of legally executed documents stating an individual’s preferences regarding various facets of psychiatric treatment in times of crisis, inpatient care, or otherwise impaired decision-making. Psychiatric instructional directives typically address issues such as preferred medications, treatments, service providers and locations, who is to be notified about hospitalizations, and which visitors are prohibited. Psychiatric proxy directives (sometimes in combination with instructional directives) allow people to designate someone to make treatment decisions on their behalf (Srebnik & LaFond, 1999). The creation and execution of psychiatric advance directives is intended to preserve consumers’ ability to engage in self-direction during times when their decision-making capacity might otherwise prohibit free expression of their preferences. By allowing individuals to state their treatment preferences ahead of time, it is more likely that care during times of psychiatric crisis and/or lack of decision-making competency will remain individualized and designed to promote a quicker return to recovery. A number of approaches to preparing mental health advance directives have been developed, including completion of paper-and-pencil checklists, use of templates available from the Internet, and working with an interactive CD-ROM on the computer.

Although there continues to be much interest in how advance directives for mental health care can promote self-determination, relatively few people with mental illnesses create advance directives or find them honored in times of crisis (Sherman, 1998). Some of the reasons for this include: lack of provider awareness of a person’s directive, concerns about individual’s competency at the time their advance directives were prepared; vaguely written directives; poor communication with proxies about treatment preferences; limited availability of desired services in many communities; advance directive revocation issues such as who can revoke a directive and when; and legal and ethical issues in implementing directives that physicians disagree with or perceive as harmful to the individual.

If medical advance directives can be viewed as attempts to ensure patient-centered care in times of diminished medical decision-making capacity, then psychiatric advance directives may be seen in the same light. Both are legal documents providing

guidance to service providers and family members about the preferences patients and consumers would express were they able to do so. As such, both types of models extend the notion of patient- or consumer-direction into situations and phases of physical and mental illness that are typically devoid of self-management.

Inpatient Seclusion and Restraint Reduction Models. Due to well-publicized injuries and deaths of psychiatric inpatients during use of seclusion and restraint, the national mental health system is experiencing a shift whereby the use of these practices is being severely curtailed or eliminated altogether (Jonikas, Cook, Rosen et al., in press). Recently, several federal agencies, such as SAMHSA, have endorsed the reduction or elimination of these procedures through targeted staff training projects and funding initiatives. At the same time, a number of programs have been developed nationally to help staff rely less often on restraint and seclusion to manage crises and violence in inpatient facilities (Carmen, Crane, Dunncliff, et al., 1996; Donat 2003; Visalli, McNasser, Johnstone et al., 1997). Like advance directives for mental health care, advance crisis management models translate directly into person-centered mental health treatment, since the person with a mental illness is integrally involved in managing his/her own psychiatric crises, and thereby, the safety of the entire inpatient setting.

One such program, the Advance Crisis Management Program, helps patients learn and document, prior to an actual crisis, their personal stress triggers and unique de-escalation strategies. Along with this, staff are trained in non-violent crisis intervention techniques (Jonikas, Laris, & Cook, 2002). Information collected from patients within the first 24 hours of admission about their stressors and calming techniques is used to create a unique crisis management plan for each patient. A copy is given to the patient and one is stored in an easily accessible desktop organizer. Plans are reviewed weekly in staff meetings and with patients. If a patient experiences difficulty managing symptoms or begins to escalate, staff and the patient implement the crisis management plan for that individual. If the crisis is averted, staff members and patients review the plan to discuss the most effective strategies and responses. If a crisis is not averted and the person had to be restrained or secluded, a staff-patient debriefing occurs to identify new crisis management techniques and revise the crisis management plan accordingly.

As with advance directives, this approach has much in common with patient-centered care. Programs to reduce use of seclusion and restraint serve as a type of “advance directive” for inpatient crises, incorporating patient’s unique symptom management techniques into a person-centered plan. As with other forms of illness self-management, providers reinforce patients’ primary and active role in managing their illness using patient-centered problem solving. Also in common with self-management approaches, care plans are individualized and developed through collaborative discussions between patients and providers.

Self-Directed Care. In self-directed care for people with mental illness, funds that would ordinarily be paid to community mental health service provider agencies are instead controlled by people with mental illness, using various formulas to account for direct, administrative, and other costs (Cook, Terrell, & Jonikas, 2004). In this model,

consumers engage in person-centered planning and creation of individual budgets, which are reviewed and approved according to a state's rules and regulations about how mental health funds may be spent. Upon approval of their budgets, consumers are given the opportunity to control financial resources using a fiscal intermediary, and direct their own care by hiring and firing service providers, and using their funds for plan-related goals such as training or transportation.

To date, only one state in the U.S. has direct, multi-year experience with a self-directed care program designed specifically for people with mental illnesses. This is the Florida Self-Directed Care Program (FloridaSDC), a behavioral health program in which participants with serious mental illnesses control the funds necessary to purchase a mix of formal and informal services and supports from providers of their choice to achieve the goals of their self-designed recovery plans (Russell, Cook et al., 2004). A purchasing arrangement using a Fiscal Intermediary (FI) is used to broaden the network of available community providers to include both private and public, professional and peer supports. The program currently serves individuals living in Northeast Florida (District 4), although plans are underway for service expansion throughout the State, including a proposed pilot program to include children with serious emotional disturbances and their families. Program participants in Northeast Florida have the option of cashing out the State designated monies that would typically be awarded to their behavioral health providers (excluding inpatient treatment, emergency services, and residential care). Once they join the program, participants disengage from traditionally contracted community-based services, although they are free to reenroll in such services at any time. Service providers join the FloridaSDC network through an Agreement of Understanding, which delineates service mission, cost rates, service access expectations, and the like.

Based on average costs of service, Medicaid eligible participants receive \$1,449 annually and non-Medicaid eligible individuals are allotted \$2,776 annually for community-based services and supports. The FI (Florida State University) receives quarterly budgetary allowances for each participant on an annual prepaid case rate basis. Through a series of adjustments, the program remains budget neutral, unless there are significant cuts in spending for the eligible population in the prior year.

The state of Oregon has recently implemented a consumer-operated "brokered" mental health program called Empowerment Initiatives that began serving participants in May 2004 (M. Hlebechuk, Personal Communication, 8/3/05). The program has 30 participants who can access services from peer or non-peer brokers and up to \$3000 to support their person-centered plans for a two-year period. Unlike FloridaSDC, in which participants disenroll from traditional services upon program entry, Oregon participants can continue to receive case management, counseling, acute care, and other services. Also unlike the FL program in which service recipients may participate indefinitely, the OR program is time-limited and individuals return to traditional services after 2 years of SDC services. Brokerage services and education from program staff are encouraged but not required. The program's fiscal intermediary is Oregon Technical Assistance Corporation, a nonprofit organization that promotes full participation in community life for individuals with disabilities, seniors and their families. Plans created thus far have

averaged 12 goals per person and cover 5 major life areas: well-being, employment, education, family and social relationships, and spirituality.

Self-directed care is a model of consumer self-management of resources for long-term care that has been shown to be effective for people with developmental and other disabilities for several years. Its availability for individuals with severe and persistent mental illnesses marks a major advance in the widespread growth of “patient-centered” care for this population. It bears a direct relationship to self-directed care models discussed at the beginning of this paper, and differs only slightly from approaches developed for those with other disabilities.

Current Availability and Use of “Patient-Centered” and “Consumer-Directed” Mental Health Care and Substance Abuse Treatment

There is a paucity of evidence regarding the availability and utilization of consumer-directed care among individuals with severe mental illness. In the early 1980s, the Epidemiologic Catchment Area (ECA) Program directly interviewed 20,291 adults in five cities (New Haven, CT; Baltimore, MD; St Louis, MO; Durham, NC; and Los Angeles, CA) and weighted the study sample according to the 1980 United States Census to estimate the number of individuals with mental disorders and their service utilization (Regier, Myers, Kramer et al., 1984). In addition to administering the National Institute of Mental Health Diagnostic Inventory Schedule (Robins, Helzer, Croughan et al., 1981) in two face-to-face interviews separated by a 12-month interval, respondents were queried about their service utilization at the baseline interview and at the 6-month study mid-point (the latter by telephone in 4 out of 5 sites). As part of the latter data collection, respondents were asked about a “newly-defined sector...called the voluntary support network (VSN) of self-help groups, family, and friends” (Regier, Narrow, Rae et al., 1993, p. 90). The VSN was defined as including 12-step and other programs for addictive and mental disorders along with an array of family management interventions such as family psycho-education and patient skills training (Hogarty, Anderson, Reiss et al., 1991) and early mental illness detection programs for patients and family members. While not overlapping entirely with the consumer-directed service approaches described in the preceding section, findings regarding the utilization of the VSN are instructive, especially when compared to the results of more recent studies.

The ECA estimated that use of self-help services for mental or addictive disorders occurred for 0.7% of the total United States population in a year, and that assistance from relatives and friends were sought by an additional 3.5%, for a total of 4.1% receiving services from the VSN sector. Of those 28.5% of the United States population estimated to have met diagnostic criteria for one or more disorders, 8.9% were assisted by the VSN sector and this sector was the sole source of assistance to 3.8% of those so diagnosed (no break-down was provided for self-help vs. assistance from family and friends). Among those diagnosed with schizophrenia, self-groups were used by 2% and help from family/friends by an additional 5% bringing the total using the VSN sector to 7%. Among those diagnosed with an affective disorder, self-help was reported by 3% and assistance from family/friends by another 9.8%, bringing the total

proportion using this sector to 12.8%. Of those with co-occurring mental health and addictive disorders, 11.4% received assistance from the VSN sector (again no breakdowns were provided); however, of those with antisocial personality disorders, a relatively large percentage - 4.8% - reported using self-help services which was correlated with high addictive disorder co-morbidity.

A nationally representative telephone and mail survey, called the Midlife Development in the United States Survey (MIDUS), was conducted in 1996 (Kessler, Mickelson & Zhao, 1997). This study used the Composite International Diagnostic Interview Short Form to diagnose major depressive episode, panic disorder, and generalized anxiety disorder. Severe mental illness was operationalized according to criteria similar to the definition used by the Substance Abuse and Mental Health Services Administration. In this study, receipt of services in the “self-help sector” was defined as attending a formal self-help or mutual-aid support group run by mental health consumers for a mental or emotional problem. Results indicated that 5.9% of those without a mental disorder and 18% of those with severe mental illness reported attending such a self-help group in the past 12 months.

Since the early 1980s, there has been a proliferation of self-help, consumer-operated, and recovery-oriented services, particularly in the public mental health sector. A survey conducted by the National Association of State Mental Program Directors Research Institute found that two-thirds of states (n=34) reported that they offer self-help programs in state psychiatric hospitals, two-thirds (n=32) routinely provide inpatients with information about community-based self-help programs, 40 states fund consumer-operated peer/mutual support programs, 38 fund consumer advocacy programs, 32 fund drop-in centers, and 32 fund consumer leadership skills training programs (Shaw, 2004). Other consumer-operated programs funded by state mental health authorities include technical assistance programs (n=25), wellness/prevention services (n=22), policy development (n=17), social services (n=16), client-staffed businesses (n=14), research activities (n=12), vocational rehabilitation/employment (n=12), housing programs (n=10), non-residential crisis intervention (n=5), case management (n=5), and residential crisis facilities (n=2). While many states report funding these services and programs, the amount of money spent on them is quite variable. For example, in 2002-2003, of 41 states reporting, over one-third (n=15) provided less than \$500,000 per year for consumer-operated services and 11 spent less than or equal to \$200,000 per year. As a proportion of total mental health expenditures, of the 37 states for which this number could be calculated (i.e., those states reporting both total annual dollar expenditures and dollar expenditures on consumer operated services) 26 states spent less than 1% on annual consumer-operated services, 8 states spent only 1%, 2 states spent 2%, and 1 state spent 3% of its total expenditures on consumer-operated services.

The most recent and nationally representative study of the use of consumer-delivered services in the U.S. is the 2002 Survey of Consumer Self-Help Entities, a national survey conducted by the Survey and Analysis Branch of the Center for Mental Health Services, SAMHSA, as part of its National Reporting Program (NRP) (Goldstrom, Campbell, Rogers et al., 2004). For the NRP's first national survey of the mental health

self-help sector, 172 counties were selected in 34 states, with probability of selection proportional to size. Within each county, organizations sought included: 1) mental health mutual support groups, defined as a group in which membership was voluntary and free, where people met regularly on the basis of a common experience or goal for the purposes of helping one another, and that was not led by therapists or professionals acting in their professional role; 2) self-help organizations, defined as entities run by and for mental health consumers and/or family members for the purposes of education, political/legal advocacy, or service provision; and 3) consumer-operated programs, defined as programs, services, or businesses controlled and operated by people who have received mental health services and staffed entirely or primarily by consumers. Groups and organizations were identified through self-help clearinghouses, mailing lists, snowball sampling, Internet searches, local newspapers, mental health associations, service delivery organizations, and other referrals. All identified entities were screened and survey data were collected via telephone interviews. Once final data were cleaned, non-response weights were calculated by region (e.g., Northeast, South) and type (e.g., mutual support, self-help, consumer-operated) to produce county total estimates that were then weighted to represent the entire U.S. using stage one weights developed for the National Co-Morbidity Survey (NCS) (Kessler, 1994).

Results of the survey revealed that, in September 2002, an estimated 7,467 groups and organizations run by and for mental health consumers and/or their families were in operation. At one point in time, there was an estimated 41,363 individuals attending mutual support groups (with an estimated average of 12 individuals per group meeting), a total of 1,005,400 belonged to a mental health self-help organization, and a total of 534,551 consumers were members/clients of consumer-operated services. While the survey's findings most likely underestimated the number of groups, organizations and services, as well as underestimated the true volume of participation, they provide a baseline for the examination of future trends.

The findings reviewed in this section suggest a "glass half-empty – glass half-full" analogy. On the one hand, there is evidence that the use of mental health self-help, mutual aid, and consumer-provided services has increased over the past several decades. In the early 1980s, the ECA study found that 8.9% of those diagnosed with a mental disorder used VSN services in a year. In 1996, the MIDUS study found that 18% of those with a severe mental illness attended a mutual-aid support group run by mental health consumers for emotional problems. In 2002, the Survey of Consumer Self-Help Entities estimated that over a million people belonged to a mental health self-help organization. On the other hand, in 2002-2003, most states spent less than one percent of their total annual mental health budgets on consumer-operated services such as mutual support, self-advocacy, and technical assistance. Writing in 2003, the President's Commission noted the need to *increase* opportunities for consumer-run services and consumer-providers in order to engage more people in traditional mental health services, enhance their access to peer support, and promote their recovery to the fullest extent possible, by increasing treatment choice and the full partnership of consumer and providers.

Effectiveness and Efficacy of “Consumer-Provided” Mental Health Care

In a recent special issue of *Psychiatric Rehabilitation Journal*, the evidence base for consumer-provided services was examined and contrasted with that of five other psychiatric rehabilitation services including case management, supported employment, supported housing, skills training, and integrated dual-diagnosis treatment for mental illness and addiction (Cook, 2004). The consensus of experts in this field was that, of all the areas examined, the evidence base was weakest in the field of services provided by and for consumers (Solomon, 2004). Yet, a surprising number of studies have been conducted using random assignment to mutual-support/consumer-operated/consumer-delivered services with results that are consistently positive.

The multi-site Consumer-Operated Services Program (COSP) funded by CMHS/SAMHSA. This study included four drop-in centers, 2 mutual support programs, and 2 educational/advocacy programs all of which: 1) were administratively controlled and operated by consumers; 2) emphasized self-help as their operational approach; and 3) had been operating for at least two years prior to the start of the study. Starting in 1999, 1,827 study participants who had made at least 3 visits to one of the aforementioned programs and were actively involved with a traditional mental health provider in the past 12 months, were assessed at baseline, 4, 8, and 12 months using a common protocol measuring outcomes such as employment, empowerment, housing, social inclusion, well-being, and satisfaction (Campbell and the COSP Steering Committee, 2004). COSP participants were predominantly Caucasian (57%), female (60%), high school graduates (64%), and diagnosed with DSM-IV Axis 1 disorders such as schizophrenia or mood disorders. The outcome variable of well-being used in preliminary analyses of data from this recently-completed study consists of a composite construct derived from validated scales measuring recovery, quality of life, empowerment, social inclusion, meaning of life, social support, and hopefulness. An intent-to-treat analysis of all sites found that participants in both experimental *and* control group conditions showed significant increases in well-being over time, with the experimental group participants achieving higher though not statistically significant levels of well-being at each study time point. Analysis of outcome data from the drop-in center sites revealed a significant three-way interaction of time, study group, and site in which well-being was significantly higher among experimental than control group participants, regardless of individual study site. While data analysis is ongoing, the early results from this study support the contention that consumer-operated service participants achieve outcomes equivalent and in some cases superior to those who receive only traditional services.

In addition to the COSP, a number of single-site random assignment studies have been conducted using a variety of consumer-operated programs as their experimental condition. Paulson and his colleagues (Clarke, Herinckx, Kinney et al., 2000; Herinckx, Kinney, Clarke et al., 1997; Paulson, Clarke, Herinckx et al., 1999) randomly assigned community mental health center clients to one of three conditions. The first was a consumer-staffed Assertive Community Treatment (ACT) team. The second was an ACT team staffed by non-consumers. Both teams were operated by a

consumer-run agency. (ACT is a model in which services are provided exclusively in the community through mobile teams comprised of psychiatrists, nurses, case managers, and other staff). In the third condition, participants received treatment as usual. Results revealed no differences between the two ACT teams in symptomatology, or any clinical or social outcome for the first two years of service delivery. However, both ACT teams had significantly greater treatment retention than usual care, and both had significantly higher hospitalization rates. The superiority of this study lies in its comparison of both consumer-directed and non-directed care with a control condition of usual care, offering support for the notion that consumer-delivered ACT services are as effective as non-consumer ACT services. This study remains the most rigorous test of consumer services in that the services tested were not adjunctive to non-consumer services, and given that a separate control group was included for the same service model (ACT), delivered by non-consumer providers. These two design features are lacking in all other randomized studies of consumer-delivered services (Solomon, 2004).

Solomon and her colleague (Solomon & Draine, 1995a, 1995b) randomly assigned clients of a community mental health center to consumer-run intensive case management versus non-consumer intensive case management. At two years, clients of both teams had equivalent behavioral symptomatology, quality of life, and a variety of clinical and social outcomes. Service delivery patterns differed, however, in that the consumer case management team provided more face-to-face services and services outside of an office setting than the control condition. At one year, clients of the consumer team were less satisfied with mental health treatment generally and had less contact with family members, but these differences did not persist at the time of two-year follow-up.

Another study randomly assigned patients released from a specialized inpatient program to a condition in which consumer and non-consumer staff worked to enhance social network development in the community and a control group that did not receive the network enhancement (Edmunson, Bedell, Archer et al., 1982). Both groups received comparable discharge planning and referral to community-based outpatient programs. Those in the consumer-delivered network enhancement condition had fewer and briefer hospitalizations than controls, and a significantly higher proportion of experimental subjects were able to function without contact with the formal mental health system than controls.

In another controlled study (Kaufmann, 1995), subjects were assigned to a consumer self-help vocational program that worked in partnership with non-consumer professional providers versus a services as usual condition that was enhanced by provision of information regarding locally available employment programs. The two-phase experimental treatment began with non-consumer professionals who provided job training, placement and support. Next, consumer-run and peer support services were delivered to enhance job seeking and provide support for commonly encountered employment difficulties. A significantly higher proportion of experimental program subjects than controls achieved employment and attained higher vocational status as measured by an ordinal ranking of steps toward competitive employment. Among unemployed subjects, experimental group participants were more likely to be looking

for a job, working as a trainee or volunteering. Among employed subjects, the experimental subjects worked a greater number of hours.

A number of quasi-experimental studies have also evaluated consumer-provided care. Felton and colleagues (Felton, Stastny, Shern et al., 1995) examined whether the addition of consumer peer specialists to an intensive case management team improved outcomes when compared to a team with a non-consumer assistants and a third team with neither consumer specialists nor non-consumer assistants. Those served by the team with a peer specialist showed greater improvement in self-image, level of social support, some aspects of quality of life, outlook, and reported fewer major life problems than did those served by the team with a non-consumer specialist and the team without a specialist or assistant of either type. Another study (Klein, Cnaan & Whitecraft, 1998) compared mental health association clients who participated in a consumer-delivered, peer support program for individuals with mental illness and substance abuse with those receiving services as usual. Compared to services as usual, participants in the peer support program experienced a significant decrease in inpatient admissions and crisis events, enhanced social functioning, reduced substance use, and improvement in some dimensions of quality of life. While these studies provide some evidence for consumer-directed services, the absence of random assignment leaves open the possibility of selection bias and fails to eliminate alternative explanations for the results that were achieved.

Writing in 2004, Solomon characterized the level of evidence for consumer-provided services as Level one, defined in her article as “At least 5 published studies with scientifically rigorous designs (randomized clinical trials, well-controlled quasi-experimental designs) using a variety of meaningful outcome measures.” The evidence cited in this report qualifies as Level 1b (“Evidence obtained from at least one randomized controlled trial”) using the United States Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) guidelines published in 1992.

Additional evidence is available regarding some of the other consumer-directed care models described in this report. For example, a number of pre-test/post-test design studies have examined the impact of *Wellness Recovery Action Planning* (WRAP) on consumers’ well-being, use of WRAP techniques, and recommendation of WRAP to other peers. The Vermont Recovery Education Project (no date) completed 23 cycles of WRAP training involving 435 participants in 1997 through 1999, 193 of whom completed pre-test and post-test evaluations for a 44% response rate. Paired, 2-tailed t-tests of mean differences for the 147 consumer WRAP participants found significant increases in consumers’ self-reported knowledge of early warning signs of psychosis, tools and skills for coping with prodromal symptoms, preference for using natural supports, support groups, and other people with mental illness for support, use of wellness tools in their daily routines, and hope for recovery. Also found were significant increases in consumers’ self-rated ability to create crisis plans, and to create plans that: expressed their needs and wishes, listed their supporters and people to contact in an emergency, and explained their early warning signs. Finally, results of paired t-test results showed that, following WRAP training, consumers reported being significantly more

comfortable asking questions and obtaining information about community services, and engaging in self-advocacy.

The state of Minnesota's evaluation of its WRAP program examined the results of 42 WRAP cycles held throughout the state in 2002 and 2003. A total of 305 mental health consumers participated, and 234 of these completed pre-tests and post-tests for a 77% response rate (Buffington, 2003). Two-tailed tests of differences in proportions revealed that, following the training, significantly greater percentages of participants self-reported having hope for recovery, taking responsibility for their own wellness, having a support system in place, managing their medications well, having a list of things to do every day in order to remain well, being aware of their symptom triggers, awareness of their early warning signs of psychosis, having a plan to deal with prodromal symptoms, having developed a crisis plan, having a lifestyle that promotes recovery, and finding it easy to engage in recovery promoting activities. Of the 234 respondents, 140 or 44% responded to a 90-day follow-up survey conducted 90 days after the end of WRAP training. All of these respondents (100%) reported feeling more hopeful about their recovery and 93% (n=130) said they had encouraged other consumers to participate in WRAP training. Since WRAP initiatives are currently ongoing in all 50 state of the United States (Copeland, Personal Communication), there are numerous opportunities to engage in further, more rigorous evaluations that can inform the field about the efficacy and effectiveness of this consumer-directed service.

The development and use of *psychiatric advance directives* (PADs) has been the subject of several evaluation studies. Sherman (1998) randomly selected 60 adults meeting criteria for severe and persistent mental illness and found that 65% were able to complete a PAD in an average of 63 minutes using interactive, multimedia software that had an 80-minute time limit. Consumer characteristics significantly related to greater likelihood of PAD completion were higher education, being Caucasian, and not having a self-reported learning disability; variables not related to completion included gender, age, diagnosis, and prior computer experience. The large majority (82%) of PADs named a surrogate/proxy, and 96% of those completing the section on medications named specific drugs or physicians they preferred while only 4% refused all medications. A study using an adapted version of the same software (Peto, Srebnik, Zick et al., in press) found that 100% of those attempting to complete a PAD were able to do so. However, support was required by around 80%: 55% required technical support, 14% needed only non-technical support, and 30% required both types of support. Assessments of competency to create PADs (Srebnik & Applebaum, in press) have found good reliability and construct validity for two measures of competency, and also that most consumers who attempt to create PADs are assessed as competent to do so.

In a survey of 30 consumers in Oregon who had prepared PADs, the large majority (85%) reported feeling empowered by PAD preparation although enthusiasm declined over time with only 54% reporting empowerment at 8 to 10-month follow-up (Backlar, 2000). Sutherby and colleagues (1999) found that one month after completing crisis cards that were similar to PADs, participants felt more involved in their care (78%), more in control of mental health problems (62%), and more likely to continue treatment (51%). A survey of 106 consumers who completed PADs (Srebnik, in press)

found a significant increase in “perceived choice” of treatment and a reduction in “perceived coercion” in treatment shortly following PAD completion, as compared with baseline assessments. In a follow-up study of 77 out of these same 106 consumers two years after PAD completion (Cook, Srebnik, Fitzgibbon et al., 2004), 89% reported that having a PAD made them feel more in control of their own treatment, 81% felt that a PAD made them feel more empowered, 80% felt that having a PAD enabled them to express treatment preferences to their case manager, 77% felt more able to express treatment preferences to their psychiatrists, and 78% felt that having a PAD made them feel more hopeful about their chances of recovery.

In another descriptive study of 64 legally executed PADs using family and provider respondents (Backlar & McFarland, 1996), ten consumers had used their PADs when in crisis and their wishes were honored in each of these ten cases. In her study of 106 individuals with legally executed PADs, Srebnik (2004) found that when clinicians were aware of PADs’ existence during mental health crises, PAD provisions were honored more than two-thirds of the time; however, PADs were accessed by clinicians in fewer than 20% of crisis events despite the existence of a 24-hour repository of PADs, substantial staff training, and efforts to alert staff to the existence of PADs using wallet cards, “dog tags,” and electronic elements.

As of June 2004, over 1200 individuals have participated in Taking Charge, the *illness self-management program* described above (VanSickle, Personal Communication). An evaluation of this program was conducted over a 5-year period (1997-2002) during which Taking Charge was implemented in an Intensive Psychiatric Rehabilitation Program in Rochester, New York (Gaylord & Nobile, 2004). During this time, 184 participants took the course one or more times. Analysis of 494 “Chance to Practice” logs kept by program participants provide actual examples of troublesome symptoms and situations, as well as the application of Taking Charge illness self-management techniques to those problems. The greatest number of examples came from the living environment, social, and recovery areas of life, with fewest from the career and education realms. The most commonly reported problematic emotional state was anger, followed in frequency by frustration, fear, depression, and anxiety. The most commonly reported physical reaction was tiredness, followed in frequency by nausea, rapid heart rate, trembling and chills, muscle tightness, and headaches. Illness management techniques reported most frequently included reframing the bodily experience intellectually by viewing the situation as “distressing but not dangerous” or remembering that “calm begets calm.” Most people reported feeling calmer after the reframing as well as feeling good about how they had handled the situation. In a separate evaluation of surveys completed by Taking Charge participants during the same time period, the same two reframing strategies were again identified as the “mental fitness tools” they used most frequently. Finally, a post-test only evaluation involved administering Giffort’s Recovery Scale (Corrigan, Giffort, Fadwa et al., 1999) six months after completion to 18 out of 25 participants in Taking Charge, for a 72% response rate. High proportions (above 75%) endorsed statements such as: “I can help myself become better” (83%); “There are things that I can do that help me deal with unwanted symptoms” (94%); I am the person most responsible for my own improvement” (83%); and “I know what helps me get better” (83%). While the small

sample size in the latter evaluation and the simple descriptive nature of the former evaluation design suggest that caution be urged in drawing any conclusions, there does appear to be some suggestive evidence that this self-management program is perceived a helpful by some participants.

Another consumer-directed program is the *Georgia Certified Peer Specialist* training and service delivery program. Since program inception in fiscal year 2000, approximately 200 consumers have been certified as peer specialists in Georgia, offering services and supports to approximately 2,500 people with mental illnesses (Fricks & Tiegren, 2004). In the fiscal year prior to the implementation of CPS services in Georgia, 100% of services were day treatment; in 2004, 27% of services were peer supports, 68% psychosocial rehabilitation, and 5% day treatment. Prior to 1999, the state spent an average of \$6,491 per consumer recipient of day treatment services; currently, the state spends an average of \$2,148 per recipient of peer supports, \$3,841 per recipient of psychosocial rehabilitation, and \$1,700 per intensive day treatment recipient (ibid).

An evaluation of the *Certified Peer Specialist Training* (Fricks & Tiegren, 2004) found that the average class size was 31 participants, with an average drop-out rate of 1 person per class. On average, 75% of participants pass the certification test on their first try and 98% pass by their second re-test. The majority of CPSs have diagnoses of depression (47%) and bipolar disorder (26%). Of 49 CPSs tracked in January, 2004, 66% were employed full-time, 22% part-time, one via a consulting contract, and 10% were unemployed. A repeated measures, non-equivalent comparison group evaluation of the outcomes of recipients of peer supports found a nearly 5% greater improvement among clients served by peer supports compared to other models (ibid).

Recovery, Inc. is a peer support organization currently operating 577 community-based *mutual-aid support groups* with an average monthly attendance of 13,158 (Garcia, Personal Communication). Two evaluation studies have surveyed Recovery group members and compared them to community residents (Galanter, 1988; Raiff, 1984). The latter study found that Recovery members who had participated in Recovery support groups for 2 or more years had lower levels of worry and higher levels of health satisfaction than did either shorter-term Recovery participants or the general public. Both groups of Recovery members rated their overall levels of life satisfaction higher than the general public.

An evaluation of mental health consumer *self-directed care* was conducted by researchers who studied the FloridaSDC program (Teague & Boaz, 2003). Data for the evaluation came from interviews with participants as well as those who had begun to enroll but later withdrew (termed non-participants); interviews with Board and community members; analysis of FloridaSDC records; and comparison of program data with administrative data from state databases. Data were collected in the spring of 2003, at a point when full enrollment had not been reached. Altogether, interviews were completed with 14 SDC participants and 8 non-participants; 18 key informants were interviewed; service records were examined for 41 SDC participants; and demographic data on 41 SDC participants were compared to administrative data on 22,222 individuals representing “the population of adult persons who received mental health services in

DCF District 4” (Teague & Boaz, 2003, p.63). Thus, while not definitive, the evaluation offered an interesting “first look” at the process and preliminary outcomes achieved at the initial stages of the program’s implementation.

The evaluation found that FloridaSDC participants met established program eligibility criteria in that they were persons considered to have serious and persistent mental illness. In addition, there were no statistically significant differences between FloridaSDC participants and a sample of adults with serious and persistent mental illnesses served in District 4 regarding age, gender, race/ethnicity, primary diagnosis, level of functioning, number of days worked, and proportion enrolled in Medicaid. The two groups also received fairly similar types of services during the three years prior to the SDC enrollment period, the only difference being that SDC participants received more Case Management and Day Treatment services, while the District-wide sample received more Crisis/Inpatient, Residential, and Other Medical services. In the interviews, however, participants’ appeared to possess greater cognitive abilities than non-participants, and enrollees were perceived by key informants as being somewhat further along in their recovery process than those choosing not to enroll.

The evaluators also focused on the availability and relative quality and accessibility of services received through the project. Interviews with participants revealed overall satisfaction with the availability of services, many of which would not have been secured without the program. In contrast, non-participants reported that they were unable to obtain important services. Observers generally confirmed that needed services were available even though some community providers chose not to enroll in the FloridaSDC provider network. The evaluators noted that members of the participant group appeared to be more engaged with and more satisfied with mental health treatment services than members of the non-participant group, and that participants rated FloridaSDC services somewhat more favorably than services they had obtained through traditional providers.

Examination of FloridaSDC service records found that participants’ recovery plans contained evidence that they were making decisions about what services they used, and showed clear linkages between participants’ stated needs and goals and the services or goods that they purchased to address these needs. Although it was too early in program’s operation to observe changes in participant outcomes, participants perceived themselves to be making good progress. They gave more positive responses than non-participants about how quickly they were moving toward attaining their goals and how satisfied they were with their rate of progress. They were more likely to think differently about their goals and to articulate specific ways in which this thinking was helpful to them.

The evaluation found that the FloridaSDC program had carefully monitored expenditures at the individual level, ensuring that participants were attentive to careful budgeting and economical purchasing. Moreover, costs per participant were found to be at or below the levels authorized per individual. In fact, for most participants, costs were significantly below authorized levels. Surprisingly however, when asked about changes in service use, participants reported an increase in overall service utilization

since enrollment. The evaluators noted that this could have reflected an increase in the use of alternative services rather than mental health services, and also that prior research has questioned the accuracy of client self-report in studies of service use. Additionally, although total resource consumption was at or below the amount allocated for covered services, the evaluators cautioned that it was too early in the program's operation to draw conclusions about potential short-term cost reduction capabilities. However, the fact that costs were below pre-authorized levels was considered to be an intriguing finding.

Finally, *programs to reduce the use of seclusion and restraint* through advance crisis management techniques are currently active in all 50 states of the U.S., although target populations and types of facilities involved in these programs vary considerably (Huckshorn, Personal Communication). Thus far, the National Association of State Mental Health Program Directors has formally trained a total of 25 states (ibid). Pre-post designs have been used to evaluate the effectiveness of these programs and to identify several active ingredients. Jonikas and her colleagues (in press) examined quarterly restraint data from the quality improvement department of a university-run hospital serving predominantly publicly funded patients approximately one year before and one year after a staff training program that emphasized teaching patients to self-manage symptom escalation was introduced in all three in-patient psychiatry units in 2002. On all three units, restraint rates decreased in the quarter after the training occurred (by 48% - 85%) and remained low (at zero or close to zero) for the remainder of that year. Before the restraint reduction program was implemented, restraint rates on the adolescent unit and clinical research units had been climbing and the general psychiatry unit's rates had fluctuated considerably. A two-way analysis of variance showed that there was a significant effect of training but no significant difference between units. Similarly, McCue and colleagues (2004) compared rates of restraint 3 years prior to and 2 years following the introduction of a staff training program that included teaching patients anger self-management techniques at a public psychiatric inpatient service and found a significant decrease in restraint rates using a 2-tailed group t-test.

The Therapeutic Importance of “Consumer-Directed ” Mental Health Care

The forgoing discussion has described the nature of consumer-directed mental health care in the United States today, along with a review of the evidence regarding its utilization, efficacy, and effectiveness. These findings have been compared with current knowledge about the nature of patient-centered care for physical illnesses, self-management of chronic medical conditions, and consumer control of long-term disability services and resources for care. This analysis has revealed that there are many parallels between the concepts of patient-centered medical care, illness self-management, consumer-directed care, and consumer-delivered care, with overlapping assumptions and strategies relating models in each of these areas to one another. These approaches share common desired outcomes for participants including increased self-confidence and self-efficacy, feelings of control over body and emotions, recovery of health and a life that is meaningful, and enhanced quality of life and material resources.

The therapeutic importance of these models of care lies in their fostering of individuals' innate inner resources for identity development and behavioral regulation. These approaches address the needs of human beings to perceive themselves as competent and to endorse their behavior as volitional in order for them to be motivated to change behavior. The critical context of relatedness to others is used to foster the internalization of new behavioral regulations (such as symptom management and changes in lifestyle) by aligning them with preexisting values and needs. By acknowledging that health is an emergent construct, sustained in social interaction with others, these models assist individuals in the healthy alignment of their identity, interpretations, and performances. Use of the patient-centered approach by definition enhances communication and relational skills, thus bolstering the individual's efforts to initiate and maintain recovery from both mental illness and addiction to drugs or alcohol.

The dissemination of consumer-centered mental health care appears to be steadily growing, and can help to ensure that these models reach a growing number of individuals faced with rebuilding their lives after a diagnosis of major mental illness or substance abuse disorder. The increasing popularity of these approaches suggests that they may continue to multiply, regardless of the presence or absence of rigorous research support for their effectiveness. This is because these types of services and supports are difficult to study using rigorous research designs, such as randomized controlled trials, given the difficulty of "assigning" study participants to what is essentially a completely voluntary service, as well as the uniquely variable nature of the services received under the mutual support/self-help/consumer-operated/ consumer-delivered/illness self-management framework.

At the same time, as noted in the 2003 President's Commission Report, the current U.S. mental health care system consists of an uncoordinated, overlapping set of programs existing at multiple governmental levels, and throughout the private sector, in which "consumers and their families do not control their own care" (New Freedom Commission on Mental Health, 2003, p. 28). This means that most consumers do not chose their own programs or providers, their needs and preferences do not determine policy and financing decisions, and care is not consumer-centered through individualized plans of care developed in full partnership between consumers and their providers (*ibid.*). Given evidence that offering a wide array of community-based services is more effective than inpatient and emergency room treatment (U.S. Department of Health and Human Services, 1999), current public policy as outlined in the Commission's recommendations is directly in-line with many of the precepts of patient-centered care. These recommendations include: the development and implementation of individualized care plans for consumers and families; involving consumers and families in service planning, evaluation, and delivery; and protecting and enhancing the rights of individuals with mental illnesses.

With all of these facts in mind, a series of recommendations is offered for enhancing the degree to which behavioral health care is "patient-centered" involving self-management of symptoms and care resources, and resulting in recovery as well as prevention of relapse and maintenance of health and well-being. The first

recommendation is to increase the level of funding for consumer-directed mental health services and supports as well as peer-based addiction recovery services, which can be accomplished by shifting financial resources away from services and service sectors that have demonstrated little or no efficacy or consumer appeal, such as day treatment or partial hospitalization. The second recommendation is for the increasing involvement of behavioral health service consumers in all levels of behavioral health care to guide system transformation and re-development along the lines of self-management and consumer self-determination. The third recommendation is for greater research attention to be paid to consumer-directed models of mental health care and addiction recovery. This may involve increasing use of participatory action research strategies that include consumers of behavioral health care in all stages of the research process, so that studies of maximum rigor can be accomplished without creating a “Hawthorne effect” that distorts the nature of the models under study. Such efforts also acknowledge and draw upon the “evaluator role” of patients engaged in illness self-management, described at the beginning of this report. A fourth recommendation is to reform the academic curriculum so that tomorrow’s mental health and addictions treatment professionals receive education and training that imparts both knowledge and experience in delivering these services and collaborating with other providers of these types of programs.

In closing, the report of the President’s New Freedom Commission on Mental Health offers a goal to which all of those working in this area can aspire...

“The Commission recommends that each adult with a serious mental illness and each child with a serious emotional disturbance have an individualized plan of care. These plans for care give consumers, families of children with serious emotional disturbances, clinicians, and other providers a genuine opportunity to construct and maintain meaningful, productive, and healing partnerships. The goals of these partnerships include: improved service coordination, making informed choices that will lead to improved individual outcomes, and ultimately achieving and sustaining recovery.” (New Freedom Commission on Mental Health, 2003, p. 35).

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