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Fact Sheet on Empowering Consumers to Maximize Control of Their Recovery: The SBHA Role¹

Health care consumers and families will need information and tools to allow them to promote and reinforce their role as the center of the behavioral health care system. At a minimum, this will include a system that supports health literacy, shared decision making, and strategies for consumers and families to direct their own behavioral health care. Health literacy is the first building block of self-care and wellness. Shared decision making should become the standard of care for all treatment services. Participant direction of services allows individuals and their caregivers (when appropriate) to choose, supervise and in some instances, purchase the effective supports they need rather than relying on professionals to manage these supports.

SBHAs have been working diligently to implement the recommendations of the New Freedom Commission especially related to enhancing recovery and promoting consumer involvement in their care. SBHAs recognize that self-directed care, implemented on a large scale, offers the potential of helping the behavioral health system move in this direction.

Self-directed care is of particular importance to the behavioral health care system because it represents one tool that can help transform the system to achieve the intent of the Olmstead decision and the President's New Freedom Commission on Mental Health.

The U.S. Supreme Court, in its 1999 *Olmstead v. L.C.* decision, determined that the unnecessary segregation of individuals with disabilities in institutions – such as public hospitals may constitute discrimination based on disability. The Court ruled that the Americans with Disabilities Act may require States to provide community-based services rather than institutional placements for consumers with disabilities.

The New Freedom Commission on Mental Health's Goal #2, "Mental Health Care Is Consumer and Family Driven" incorporates a series of recommendations, several of which relate to self-directed care:

- Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.
- Involve consumers and families fully in orienting the behavioral health system toward recovery.

¹ SBHAs are state substance abuse and mental health authorities, and the term *behavioral health* refers to substance abuse and mental health.

Align relevant Federal programs to improve access and accountability for behavioral health services.

- Protect and enhance the rights of people with behavioral health conditions.

In the Commission’s vision, these plans “should form the basis for care that is both consumer-centered and coordinated across different programs and agencies. The funding for the plan would then follow the consumer, based on their individualized care plan,” (NFC, 2003, p. 35).

In its already classic report, *Crossing the Quality Chasm*, the Committee on Quality of Health Care in America of the Institute of Medicine (IOM) of the National Academy of Sciences proposed six major aims for the health care system. It should, they said, be “safe, effective, patient-centered, timely, efficient, and equitable.” The report, focused primarily on the physical health care system, and identified several dimensions of patient-centered care including (IOM, 2001, pp. 49-50):

- Respect for patients’ values, preferences, and expressed needs;
- Coordination and integration of care;
- Information, communication, and education; and
- Physical comfort

SBHAs apply many of the principles of self-directed care highlighted in the NFC and IOM reports in their programs and policies. The Comprehensive Community Mental Health Services Program for Children and Their Families (Systems of Care) that SBHAs promote, include involving families of children, and children themselves when feasible, in making decisions about services.

SBHAs emphasize peer-to-peer recovery support services that help prevent relapse and promote sustained recovery from severe behavioral health disorders.

SBHAs are developing – and helping behavioral health care consumers and families access – user-friendly information on the effectiveness of available services in order that they may truly make informed health care decisions.