

Guidelines for Consumer and Family Participation

Applicants should have experience or track record of involving mental health consumers and their family members. The applicant organization should have a documented history of positive programmatic involvement of recipients of mental health services and their family members. This involvement should be meaningful and span all aspects of the organization's activities as described below:

Program Mission - An organization's mission should reflect the value of involving consumers and family members in order to improve outcomes.

Program Planning - Consumers and family members are involved in substantial numbers in the conceptualization of initiatives including identifying community needs, goals and objectives, and innovative approaches. This includes participation in grant application development including budget submissions. Approaches should also incorporate peer support methods.

Training and Staffing - The staff of the organization should have substantive training in and be familiar with consumer and family-related issues. Attention should be placed on staffing the initiative with people who are themselves consumers or family members. Such staff should be paid commensurate with their work and in parity with other staff.

Informed Consent - Recipients of project services should be fully informed of the benefits and risks of services and make a voluntary decision, without threats or coercion, to receive or reject services at any time.

Rights Protection - Consumers and family members must be fully informed of all of their rights including those designated by the President's Advisory Commission's Healthcare Consumer Bill of Rights and Responsibilities: information disclosure, choice of providers and plans, access to emergency services, participation in treatment decisions, respect and non-discrimination, confidentiality of healthcare information, complaints and appeals, and consumer responsibilities.

Program Administration, Governance, and Policy Determination - Consumers and family members should be hired in key management roles to provide project oversight and guidance. Consumers and family members should sit on all Boards of Directors, Steering Committees and Advisory bodies in meaningful numbers. Such members should be fully trained and compensated for their activities.

Program Evaluation - Consumers and family members should be integrally involved in designing and carrying out all research and program evaluation activities. This includes determining research questions, designing instruments, conducting surveys and other research methods, and analyzing data and determining conclusions. This includes consumers and family members being involved in all submission of journal articles. Evaluation and research should also include consumer satisfaction and dissatisfaction measures.

