

# THE NEW FRONTIER

Effective Strategies for Promoting and Sustaining the  
Meaningful Involvement of Consumers, Families and  
Youth in State Mental Health Transformation Activities

# RATIONALES FOR CFY INVOLVEMENT

- Key informants about disconnects and barriers in the systems.
- Knowledge of constituents.
- Key informants about legal, policy, institutional barriers to meaningful involvement in systems change.
- Possess historical memory of previous initiatives.
- Possess skills, knowledge and work experience to effectively partner in all transformation activities.
- Provide institutional memory for subsequent administrations and departments.

# OVERVIEW OF PRESENTATION

- Rationales for CFY involvement
- Ten common challenges to meaningful involvement
- Model strategies for overcoming challenges

# Ten Common Challenges to the Meaningful Involvement of CFY

- Avoidance of stigma and discrimination and their impact on attitudes regarding the “ability” of CFY to be genuine partners in systems transformation and change.
- No consensus reached on the definitions of members of the CFY “class” and underestimating the diversity within each group.
- No clear definitions of what will constitute “meaningful involvement” through all stages of the transformation process.
- No clear definitions of what will constitute a CFY “driven system”.
- Identification and elimination of legal/administrative barriers impacting upon “meaningful involvement”.
- Underestimating the need to eliminate financial disincentives and create incentives.
- Underestimating the need for training and support for key staff, transformation agents and champions to successfully engage in new and often complex roles and tasks.
- Underestimating the range of skills and talents that CFY possess or are capable of learning.
- Fatigue of many stakeholders previously involved in systems change.
- Unrealistic expectations regarding the pace and complexity of systems change.

# IMPACT OF STIGMA AND DISCRIMINATION ON INVOLVEMENT

- Stigma impacts on everyone's beliefs about the abilities of consumers, family members and youth to be actively involved in all aspects of systems transformation and change.
- Self-stigma impacts on the belief that consumers, family members and youth have in their abilities to be successfully involved in all aspects of systems transformation and change.
- Facially neutral policies or practices often have a disparate impact on the ability of some consumers, family and youth to become involved in systems transformation and change. There is no intention to discriminate but the policy or practice may impact upon an individual's or a group of individuals' ability to become involved.
- Meaningful involvement requires developing strategies for combating stigma, self-stigmatization and the identification and elimination of neutral policies and practices that may negatively impact upon the involvement of some consumers, family members and youth.
- Meaningful involvement also requires the adoption of affirmative and proactive strategies that promote access and inclusion.

## Example of Neutral Policies Having a Disparate Impact

- State Travel Advance and Expense Reimbursement Policies
- Policy: To reduce fraud and theft many states have policies against providing cash advances for travel and meals.
- Disparate Impact: Many consumers, even those with work histories may not have savings or credit cards that may be used to cover these expenses.
- Outcome: Limited participation in activities require travel and accommodations. Financial hardship caused by adhering to policy.
- Possible Solution: Create financial hardship exception to the policy OR use another not-for-profit agency as a fiscal pass through.

## Strategies for Overcoming the Challenges

CFY can and should be partners in identifying challenges and developing strategies to overcome these challenges.

Widening the Net: Conduct a qualitative and quantitative inventory of CFY groups, leaders and community champions. Learn as much as you can about who they are and what they do. Avoid relying solely upon provider agencies and their leadership to identify these resources for you.

## CFY Involvement Workgroup

Several states have created CFY Workgroups or Advisory Groups whose goals are to increase the involvement of CFY in state mental health transformation activities.

# Model Tasks for Workgroup

- Defining membership of each class, “meaningful involvement” and “consumer, family and youth driven”
- Identifying formal roles for CFY in transformation activities
- Development of model job or task descriptions
- Identifying additional challenges and policy recommendations strategies for overcoming challenges
- Identifying areas for technical assistance and training
- Recruitment and outreach strategies
- Budget for activities

# Examples of CFY Workgroup Activities in MH-TSIG States

- CFY Involvement Standards- Oklahoma
- Travel Advance and Reimbursement Policy- Missouri
- Consumer Engagement Plan-Missouri, Texas and New Mexico
- Review of Workgroup Recommendations- Connecticut
- Legislative Priorities- Washington State

# Some Additional Tips

- Give special attention involving seniors, consumers residing in state facilities including hospitals and prisons, traditional CFY groups frequently have not included these groups in their memberships, activities or outreach efforts.
- Racial and ethnic minorities may be “off the radar” and engagement may require the identification and utilization of “champions” operating outside of traditional mental health, criminal justice and substance abuse systems.
- Cultural differences including the role of the individual vs. the collective, language and attitudes towards mental illness must be incorporated into outreach strategies.

## Prism of Mental Illness

- Avoid viewing your potential partners through the prism of mental illness. CFY possess many strengths, talents and skills that can be assets as you move forward. Preparation, ease of access and meaningful involvement are the cornerstones of their participation in transformation activities.