

Avenues for Consumer Engagement to Shape Medicaid Managed Long-Term Services and Supports

The development of Medicaid Managed long-term services and supports (LTSS) in any state creates openings for consumer engagement. To mitigate the risks and maximize the potential benefits of the program, consumer advocates must get involved when the program is first planned and stay involved as it unfolds.



Intervention Points: Following are common openings for engagement, although states may seek to restrict consumer involvement in some aspects of the process.

- **Initial planning** gather allies; consult experts; meet with state officials, managed care organizations (MCOs) and providers; involve legislative champions; develop consumer principles and recommendations; begin discussions with officials at the US Centers for Medicare & Medicaid Services (CMS)
- **Development of waiver applications or Medicaid state plan amendments** comment on state drafts, bring allies and consumers to hearings, engage Legislative oversight committees, comment to CMS officials

- **Development of requests for proposals and contracts with MCOs** meet with state officials, review drafts, talk with MCO officials, check MCO experience in other states
- **State review of plan readiness** identify areas of concern, seek to participate in state review, review readiness reports, assess provider network adequacy using secret shoppers
- **Consumer outreach materials and consumer handbooks** meet with state officials, review materials, review draft contracts for enrollment brokers if used, work with community based organizations to educate consumers
- **Performance reviews**, including external quality reviews and consumer surveys give input to state officials on measures and questions, review reports, monitor quality outcomes, monitor grievances and appeals
- **Oversight** seek appointment to state advisory committees and MCO boards or advisory committees, support other consumer representatives, engage with ombudsmen, review plan reports to state, use secret shoppers to test cultural and linguistic competency and compliance with disability access laws, inform federal officials of major problems

Potential Allies: Seeking common ground with other interested parties can help strengthen consumer advocates' voices at every intervention point. Coalition building is always challenging and requires learning about and acknowledging shared interests and differences. Bridging the priorities and perspectives of seniors and people with disabilities adds another layer of complexity. Even the language of the independent living movement and that of advocates for frail seniors is different in describing their visions of quality care. To come together may require many discussions, including community forums to explore commonalities. Developing shared principles is an important tactic.

Below is a short checklist of the most likely potential allies:

- Geriatric providers doctors and other providers trained in serving seniors
- **Community providers** of LTSS
- **Referral and advocacy agencies**, such as Area Agencies on Aging, Aging and Disability Resource Centers, Independent Living Centers and Councils, and Recovery Learning Communities for people with mental illness or substance use disorders
- Unions and associations representing LTSS workers
- **Organizations representing** seniors, people with physical, mental, intellectual and developmental disabilities, people with substance use disorders, homeless individuals and low-income consumers
- Mission-driven managed care plans (typically non-profit plans)
- **National advocates**, including Community Catalyst, National Senior Citizens Law Center, Disability Rights Education & Defense Fund, AARP, National Health Law Program, and Families USA

To learn more about Medicaid managed LTSS, see *Putting Consumers First: Promising Practices for Medicaid Managed Long-Term Services and Supports.*

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