# Key Advocacy Steps for Advocating on Managed Care Plans

As officials in the states and federal government wrestle with budget deficits and growing healthcare costs, one growing response is to institute managed care plans for people with disabilities and seniors, including ones for people eligible for Medicaid and Medicare, the so-called duals.

There are concerns around managed care. But plans are coming and the alternative may simply be cutting services. It may not be enough to simply say “NO!” Disability rights activists, consumers, and independent living centers must be involved in the discussion.

## Some concerns with managed care

Many managed care programs for people with disabilities fall short because of operational issues, including:

* Long wait lists or limited provider capacity.
* Fragmented delivery models and limited benefits packages.
* Provider ignorance of long term services and supports (LTSS) and its fundamental role in independence, integration, and wellness for people with disabilities, resulting in continued emphasis on the medical model of disability.
* Provider actions to obtain short-term savings by limiting LTSS.

## Making managed care work for people with disabilities!

A managed care plan does not have to be bad. Some good things a managed care plan can do:

* It can support community-based services over institutionalization!
* It can build home and community-based services that support independence, recovery, and integration!
* It can provide a holistic approach to healthcare that integrates long term services and supports with primary care, reducing the primacy of the medical model!
* It can result in true patient-centered care based on consumer direction and accessibility of services!

Health reform broadly considered will take many forms, good and bad, from implementation of the Affordable Care Act to cutting services at the state level. But one thing is certain. If people are not at the table expressing their needs, we’ll get poor care, poor services, and reduced opportunity for many to live independently.

## Getting Involved

Some key steps to getting involved include the following:

1. Know what your state plans do around managed care. Ask your state’s Medicaid and human services administrators if there are plans to institute managed care. Also reach out to regional offices for the Centers for Medicare & Medicaid Services (CMS), which will be closely involved with states in rolling out managed care for people with disabilities.

2. Get involved early. Demand transparency and input in the design and composition of plans, the approval process, oversight mechanisms, and review of outcomes. This discussion can be had with your state officials, CMS, and managed care organizations.

3. Build allies. Much about a health insurance plan is technical; enlist the support of healthcare advocates and legal services attorneys, who can weave through the pages of rules and regulations. Also build alliances with various disability and senior groups.

4. Engage those who’ll be served by plans. Build our consumer voice, and speak out on basic principles:

* We want consumer-directed services.
* We want choice in services and providers.
* We want protections such as appeal rights and ombudspersons.
* We want services accessible to people with disabilities and compliant with the ADA.
* We want extensive LTSS such as PAS and DME, and roles for advocates in coordination of services.
* We want financing mechanisms that adequately support providers and that give incentives for LTSS, penalize institutionalization, and do not cut services for short-term savings.

Do not be intimidated by the technical nature of health insurance plans. Consumer direction, choice, and adequate care and services are not complicated! Speak truth to power.

5. Engage state officials throughout processes. Request public forums, and if they are not held or are not timely, hold your own forums. Be sure you get documents; they should be public record. And if you can work in collaboration with state officials, all the better.

6. Engage managed care organizations. There may be requirements that they work with program enrollees, and be sure to ask officials at all levels for this. In a majority of instances, managed care staff will not know about consumer direction, recovery models for mental health, family supports for people with intellectual disabilities, and independent living.

* Ask for meaningful advisory roles.
* Provide ongoing trainings and oversight on matters such as LTSS.
* Provide input on program design around LTSS and other elements of care and services.
* Work on assessment processes and outcome measures that consider consumers’ ability to live independently in the community, including going to work and using transportation and living in accessible and integrated housing.

7. And when things are not right, take action! Oppose processes that exclude us. Oppose cuts to LTSS. Oppose lack of consumer rights and compliance with the ADA and Olmstead. And be sure to offer new ideas and good ideas and keep engaged.

We know advocacy!

We know independent living!

Healthcare advocacy is disability rights!

Organize! Advocate! Agitate! Educate! Engage!

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