Aged, Blind and Disabled Task Force Questionnaire
Response from The Arc of Indiana & Self-Advocates of Indiana
July 22, 2013

1. What goals and outcomes should a Medicaid managed care program for the aged, blind and disabled strive to achieve?

New systems must be built with a focus on care coordination, be person-centered, coordinated locally by those who know individuals the best, and offer high quality, affordable, cost-effective care

It must provides high satisfaction to the individuals receiving care, along with a strong understanding of how their systems of care work

It must be driven by individual needs that include a holistic look at the person - employment, housing and total health must be considered and coordinated in a holistic approach

Coordinates preventative, acute and long-term services through the use of a strong "health home" that understand the needs of individuals receiving services, as well as their families and caregivers

Prioritizes the use of home and community-based supports and engages people in wisely spending resources that meet their needs

Provides for the integration of behavioral/mental health and physical health - including crisis care

Utilizes the experience of community based providers who have a long and successful history of working with people with disabilities and who understand them and their community

Offers networks that include all willing and qualified providers

Addresses the need for quality, preventative dental care for adults as well as children

Carefully considers access to care for people in rural areas

Addresses the need for transportation

Provides expedient access to services for families and individuals in crisis

2. What barriers exist in achieving comprehensive coordinated care for aged, blind and disabled Medicaid enrollees?

Current health/long-term care system outcomes are not getting the results people want or need. Many people with disabilities are not offered basic health/wellness options, health care screenings, or preventative health care

Current system is expensive and lacks the flexibility to direct funding to address the right needs at the right time

There is a lack of communication, and incentives for communication, among PCPs, long-term care providers, and acute care providers

Transportation is a tremendous barrier to both acute and long-term care supports

Note: It would be interesting and helpful for FSSA to review the number of mammograms provided to adult women with disabilities in the recommended age ranged for this procedure

3. What problems exist under the current program infrastructure and design that the State should strive to address?

Quality care is not available consistently throughout the state. A network of providers trained to address the needs of individuals with disabilities, along with accessible equipment and facilities must be available statewide.

Individuals are often disconnected from both the buying decision and decisions about what is to be offered

Rates that are designed to control spending often control access, leading to greater expenditures in health and long-term care

People who have never met or will never meet individuals are often making life changing decisions as it relates to their long-term care

State infrastructure has not kept up with technology or demand. As an example, BDDS offices have not been redesigned in size or scope to address the focus on home and communities based supports, rather than institutional care, and have become a choke point rather than a resource

State technology has not been allowed to keep up with efficient ways to support the infrastructure

There is no organized training system in place for state agencies, providers, families, and individuals receiving services that leads to desired outcomes

There must be greater access to crisis care to avoid higher cost long-term care

Individuals receiving services have no mechanism to know what is being spent, or to redirect resources to services that would be more effective for them

4. What works today in the delivery and management of care for aged, blind and disabled enrollees that should be preserved?

Medicaid Waivers have dramatically bent the spending curve of the past – shifting funding from costly institutional spending to a focus on home and community based care

With the support of home and community based supports, more individuals with disabilities than ever before are living in their communities with non-24 hour supports

More individuals with disabilities are employed thanks to supports and training provided by the Medicaid Waiver

Basic health care access is improving, but continues to be limited in many areas

Giving families and individuals choice in the selection of their providers for Medicaid Waiver services is critically important and is well received

5. Are there any populations which should be excluded from enrollment in a managed care model? Why?

This is a very difficult question to answer without first knowing more about the model. If managed care is done thoughtfully, designed in a way to result in positive outcomes, and focused on a care coordination model, enrollment should be very broad. If managed care is poorly constructed, based only on cost savings, no one should be enrolled.

6. Are there any services that should be carved-out from managed-care model? Why?

We have given this very careful consideration. While there are arguments on both sides, we believe initially a carve-out, that offers both acute and long-term care supports in a holistic way, should be provided for children and adults with intellectual or developmental disabilities.

Consideration should be given to developing Coordinated Care Organizations (CCOs) - locally governed partnerships of health care providers, community providers, and community members that offer a quality-based, creative and cost effective way to address community needs. CCOs can include hospitals, physician groups, pharmacies, community-based providers, behavioral health, etc., who share financial responsibility and risk with the state Medicaid agency.

7. How should quality outcomes of a managed care program for the aged, blind and disabled is measured?

Studies show that better care leads to lower costs, and that it takes time to address the acute care needs of people with disabilities and the elderly, whose needs have often been neglected or underserved. It is also important to develop quality outcome measures that address the unique needs of these different populations. Outcome measures for a 30 year old man with Down syndrome should be very different than outcome measures of an 80 year old woman with dementia.

Quality outcome measures should be developed through a process involving people with disabilities, family members, providers, advocacy groups and state officials to appropriately track progress in the following areas:

- Locally based care coordination
- Individualized/Person-Centered Care
- Family Focused Care
- Coordination of all care providers
- Process – are individuals receiving care they need when they need it and are they following through with recommendations of care providers
- Positive health outcomes
- Access to inclusive, community based programs
- Access to preventative care
- Access to services resulting in employment
- Coordination with natural supports
- Direct Support Staff workforce development- including training, wages and new and creative incentives for quality outcomes
- Flexibility in developing and accepting new models of service

8. What are the advantages and disadvantages of a managed care model for the aged, blind and disabled?

If developed in a thoughtful way, in collaboration with people with disabilities, families and providers, managed care could provide a cost-effective approach to preventative, acute and long-term health care. It is important that stakeholders - including people with disabilities, family members, caregivers and the broad range of providers that support this population - have a voice in the overall design, how any managed care contract is written, and the design and selection of MCO's – including how provider selection criteria, benefit plans and implementation plans are developed.

It is essential that those receiving services have choices in selecting providers for both primary and long-term care. Services must be readily available and physically accessible so that individuals can receive a wide range of sound preventative, acute and long-term services through providers who are familiar with their needs and who involve them in decision making.

A successful managed care program must engage individuals in a shared savings concept that incentivizes the wise use of resources. Individuals receiving services must be engaged in developing healthy lifestyles and understanding the importance of the effective use of limited resources, particularly in regard to long term care.

The system of home and community based services must be designed in a way that allows families to trust the system enough to use only what they need, knowing that, if needed later, funding will be available to take care of new needs.

9. What additional concerns do you have regarding management of these populations that the Task Force should take into consideration?

During the past legislative session a number of "managed care" proposals were proposed. Most were not well received by the disability community and some drew strong opposition. None responded in a comprehensive way, as outlined above.

A simple cost savings proposal would only exacerbate the existing crisis and lead to greater spending or denial of services to a population of people that is in dire need of a system of services that provides knowledgeable and coordinated care.

If stakeholders continue to view reform efforts only as a "managed care" issue, rather than a care coordination opportunity, the needs of people with disabilities will continue to go unmet, and goals to provide services in a more cost effective manner, will not be achieved.

10. Do you have a proposal or ideas you would like to present to the Task Force? If yes please provide your name and contact information.

Yes, we would welcome the opportunity to present to the task force.

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