



NH Medicaid Care Management
Long Term Care Consumer Feedback

May 2012

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“Thank you. I’ve received a lot of help over the course of my life. I’ve realized how much the Department cares. I want to help influence the Medicaid for Employed Adults with Disabilities program.”

Background

The New Hampshire Department of Health and Human Services is in the process of transitioning the state’s Medicaid delivery system from the fee for service model to care management. Step 2 of the transition will include Long Term Care (LTC) services and supports.

The purpose of this project was to understand consumer/client perspectives on the current Medicaid/LTC system and what might be done to improve it (or to maintain its quality) under a care management model. Its aim was to build on the consumer feedback obtained through the Department’s six Medicaid Care Management Program public forums and ten consumer focus groups held in the fall of 2011.

The approach was to work directly with two client groups: family members of consumers with developmental disabilities currently served by the Area Agency system; and family members and consumers of the Choices for Independence Program (CFI) which provides services to elderly citizens and to people with physical disabilities.

Local human service providers helped recruit consumers and family members who assist clients with applying, qualifying and the on-going navigation of the Medicaid long-term care service delivery system.

Each work group objective was to ask consumers to describe the system’s current state from their point of view from the time they applied for services through the on-going receipt of services paid for by the state’s Medicaid program, and then to ask them what could be done to improve the system to make it work better for them.

A process improvement expert from the Department facilitated the sessions using a modified LEAN approach (a quality and process improvement strategy) to probe these issues by:

- Identifying system pain points currently experienced by Medicaid LTC consumers.
- Identifying areas that can be improved in the current process from eligibility to receipt of services.
- Collecting ideas from service consumers and identifying opportunities for improvement that could contribute to the design of a care management program for long term care services.

As a result, a system process map based on CFI consumer feedback was developed and is included as Appendix 1 of this report on page 13.

“People with disabilities should work with the people in charge of Medicaid care management so it’s of mutual benefit to both sides.”

Summary

The initial plan was to hold three, two-hour work group sessions with 8-12 representatives of the two client groups with the intention of more fully understanding the process for qualifying for and receiving waived services from their perspective.

Developmental Disability Consumer Work Group

The project team conducted one session with the developmental disability work group. Upon its completion it was agreed that at this time it did not make sense to continue meeting until further details of the care management program were publically available.

As was clearly expressed to us in that one session, from the perspective of families who use it, **the system of community-based care delivery and support for people with disabilities in New Hampshire is innovative, cost effective and of high quality.** The Area Agency system is directed by consumers and their families and anticipates and responds to the individual needs of people who need help in caring for their loved ones and keeping them at home and in the community.

From the consumer perspective, the Developmental Disability system as it currently exists in New Hampshire is care management. It is highly cost-effective and high quality. Faced with a transition to care management for long-term care services and supports, consumers fear a loss in control over service quality and scorn the idea that a corporate care management organization can deliver services that meet their needs more cost effectively.

Choices for Independence Work Group

The project team held three sessions with individuals currently receiving services through Medicaid for Employed Adults with Disabilities (MEAD) and/or the Choices for Independence Medicaid waiver programs.

Choices for Independence provides home and community-based services like adult day care, in-home medical care, personal care, skilled nursing and non-medical transportation to help people stay in their homes and continue to live independently. The MEAD program provides Medicaid coverage to adults with disabilities who have substantial care needs and are working and therefore would not otherwise be financially eligible for Medicaid.

These sessions probed what in the system of care is currently working well, where there are challenges and what could be improved for the future.

Overall, the participants in this work group said that the **intake process is confusing and cumbersome and can be demeaning**. However, once they are deemed eligible and are receiving services they **were generally happy with the care that they were able to access**, and felt it greatly improved the quality of their lives.

The system process map developed based on CFI consumer feedback is included as Appendix 1 of this report on page 13.

All direct quotes used in this report are from work group participants whose confidentiality was assured and whose opinions reflect their own experience, and may not necessarily be indicative of the experience of everyone who receives similar services through the N.H. Department of Health and Human Services.

“What you have here are parents who are very involved and very knowledgeable. We cannot throw away the piece that is working very well. You have everything you need to know.”

Work group session feedback from Developmental Disability consumers

From the perspective of people who use it, the system of community-based care delivery and support for people with developmental disabilities in New Hampshire is **innovative, cost effective and of high quality**. The Area Agency system is directed by consumers and their families and anticipates and responds to the individual needs of people who need help in caring for their loved ones and keeping them at home and in the community.

From the consumer perspective, **the Developmental Disability system as it currently exists in New Hampshire is care management**. It is highly cost-effective and high quality. Faced with a transition to care management for long-term care services and supports, consumers fear a loss in control over service quality and scorn the idea that a corporate care management organization can deliver services that meet their needs more cost effectively.

For example, from their perspective, in the current state:

- Families receiving in-home services and supports develop and stick to annual budgets (capitation) in consultation with their Area Agency.
- Families and agencies, whenever possible, develop common sense, low-cost solutions to meeting needs and providing services (for example, paying for a YMCA membership rather than more expensive physical therapy, or purchasing an annual bus pass rather than paying someone to drive a consumer).
- Keeping a loved one at home or living independently with supports in the community costs much less than institutional placement.
- The system is flexible and responds quickly to crises and emergencies.
- Area Agencies and the families that run them have harnessed the capabilities of hundreds of volunteers who assist each other in navigating the service system and providing emotional and technical support.

Families feel they have a strong and supportive relationship with the Department of Health and Human Services and **are concerned that interjecting a care management organization as a gatekeeper into the mix will result in less flexible, less person-centered, less innovative, lower quality decision making and services.**

There is great concern that a transition to care management for people with disabilities will undercut or unravel all of the work that the families who love them have put into building up a community based system of care since the closing of the Laconia State School. This system is a lifeboat in a storm for many families faced with the challenge of caring for a loved one with a disability.

From the comments of those participating in the initial work group session, it appears that the existing system of long-term care for people with developmental disabilities meets all of the Department's Medicaid Care Management Program Guiding Principles (page 20).

Given the apparent high level of customer satisfaction with the current state, the question that stakeholders in the current service delivery system ask is: **Would a future system, under the oversight of a Managed Care Organization, serve people better, and be as, or more, cost effective?**

Given the reported "off the books" value of volunteer services and the highly individualized nature of the current service system, it would appear to be of value to develop a set benchmarks or criteria that a managed care organization would have to meet or beat in order to take over the management of the State's developmental disability long term care services from the current Area Agency service delivery system.

What consumers want to know is, can a managed care organization do a better job at coordinating care for people with disabilities in New Hampshire in terms of access, price, quality and customer satisfaction?

“It took over 90 days and it took everything my mother had in terms of resources to get this done. When we got it, I broke down and cried.”

Feedback from Choices For Independence work group sessions

Current state

Generally **people are happy with the Choices for Independence (CFI) program** once they are approved for eligibility. With basic supports in place, participants and/or caregivers are better able to work, to advance their education, to make contributions to society, live longer and stay healthier.

Intake

The intake process is a challenge for many participants. As one participant said, “The process felt like a series of hoops to jump through, only they did not give you all of the information. I needed to keep asking and asking what was next.” However, some sophisticated consumers appear to be able to navigate the system with success. As one said, “Some intakes are great. They were very friendly intake people. I called ahead of time.”

Financial eligibility was the biggest hurdle – not the level of medical need. Although the work group participants understood this, they said it is hard when a person is made to feel like their medical/care needs are not even considered until the end of the eligibility process, when they are struggling to deal with their care needs every day. A number of participants incurred significant financial loss – foreclosure, loss of vehicles – as they struggled to get an elderly or disabled family member qualified for the CFI waiver.

The level of paperwork is burdensome and it can be difficult to know what to keep and what to not to keep. Some financial records required go back as many as 6 years. Work group participants said that increased communication and increased use of technology might make this easier.

“If I am disabled at 8, I will be disabled at 18 and at 21 – let’s look at long range planning. For MEAD, I started planning in high school.”

Resources available

Work group participants told us that it is **hard to identify how to initiate the process when applying** for assistance. The process is helped by support from outside providers.

For example, **ServiceLink is a great resource** work group participants said. The agency is very helpful in guiding individuals through the process of receiving care under the CFI waiver. **Granite State Independent Living, adult day centers like TLC in Concord, and Case Management services like LifeCoping** were also mentioned as being very helpful.

Communication

What came through loud and clear is that improved communication is key. **The most knowledgeable consumers appear to fare the best in this system.** Work group participants said that it is very important for disabled people to be empowered and able to manage their own care. As one participant said, “It’s the responsibility of the Department to make the rules available to me, and it’s my responsibility to use that knowledge to get the best services I can for myself.”

They said that, currently, **there is not enough communication within the Medicaid LTC system**, both in how to navigate it and in changes to it as they are made. The most significant frustration, participants said, is that those who administer the system don’t seem to understand it themselves. As one person said, “The right hand does not know what the left hand is doing and the technology improvements do not seem to be helping.”

The DHHS website helps in that it provides contact information, but it **does not have the depth of information** that is needed to meet consumer needs, they said. It is not generally regarded as being very user friendly. One work group participant termed it “a virtual run around.”

Incorporating more real time communication was suggested. “Maybe a blog or something that people can follow to keep themselves informed.”

“It would be nice to know where to go for help without having to stumble across it.”

Program Design

Advance planning is key. Workgroup participants said that advance planning is crucial, both for elderly clients as they decline and for individuals living with disabilities.

The **MEAD program works, but has not evolved to fully meet the needs of the clients.** The PCSP/PCA (types of personal care attendants) designation impacts the ability of MEAD recipients to be fully independent. For example, PCAs cannot transport clients to handle daily tasks like grocery shopping, but PCSPs can.

Future State

Participants said that there is a huge need for **increased transportation supports.** The existing services do not accommodate all life needs and restrict people’s ability to live fully independently.

The work group participants were eager to remain involved to ensure that **personal care hours are not further limited under care management or become more inflexible.** Personal care is crucial for people with physical disabilities to be able to live independently in the community and maintain the quality of their lives.

Many issues could be avoided if **skilled staff conducted assessments and participated in the development of service plans.** There was also a request that, if possible, evaluations should be conducted in-home and not over the phone – this can enable consumers to be seen, and their needs evaluated, in their own environment.

“Work group meetings like this are valuable and should continue through Medicaid Managed Care implementation.”

Open questions

These are questions/suggestions work group participants would like to have considered in future program design.

- Could MEAD participants be offered Health Care Accounts to set aside tax-deferred or tax-exempt funds for health care needs?
- Could MEAD participants be allowed to protect more resources (for example keep everything accrued/saved up until time of dismissal or retirement from job)? The unintended consequence of marriage, job loss (with severance pay) or retirement potentially cuts a participant, who has severe physical care needs, off from services. From their perspective, this would be a financial disaster.
- Could assets/resources received through other programs a consumer is eligible for be exempted from Medicaid eligibility criteria? For example, should Social Security be counted as a resource against Medicaid financial eligibility?

Suggested next steps

Participants suggested that **the Department should continue to hold work groups** like the one they had just participated in. They said that DHHS and the managed care organizations should continue to involve consumers as the care management transition is implemented.

They are interested in providing ongoing feedback about what’s working and not working as the system rolls out. They are also interested in being more involved, particularly in the area of changes to MEAD and other employment policy issues.

Outside of work groups, the participants are interested in increased opportunities to provide input and share experience. They offered ideas to facilitate this such as a blog, or an open message board.

Finally, **CFI work group participants expressed thanks for the assistance** they had received and for how much DHHS does for them. They also expressed appreciation that DHHS took time to listen to what people are saying because these changes will make a difference in their lives.

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Project Team

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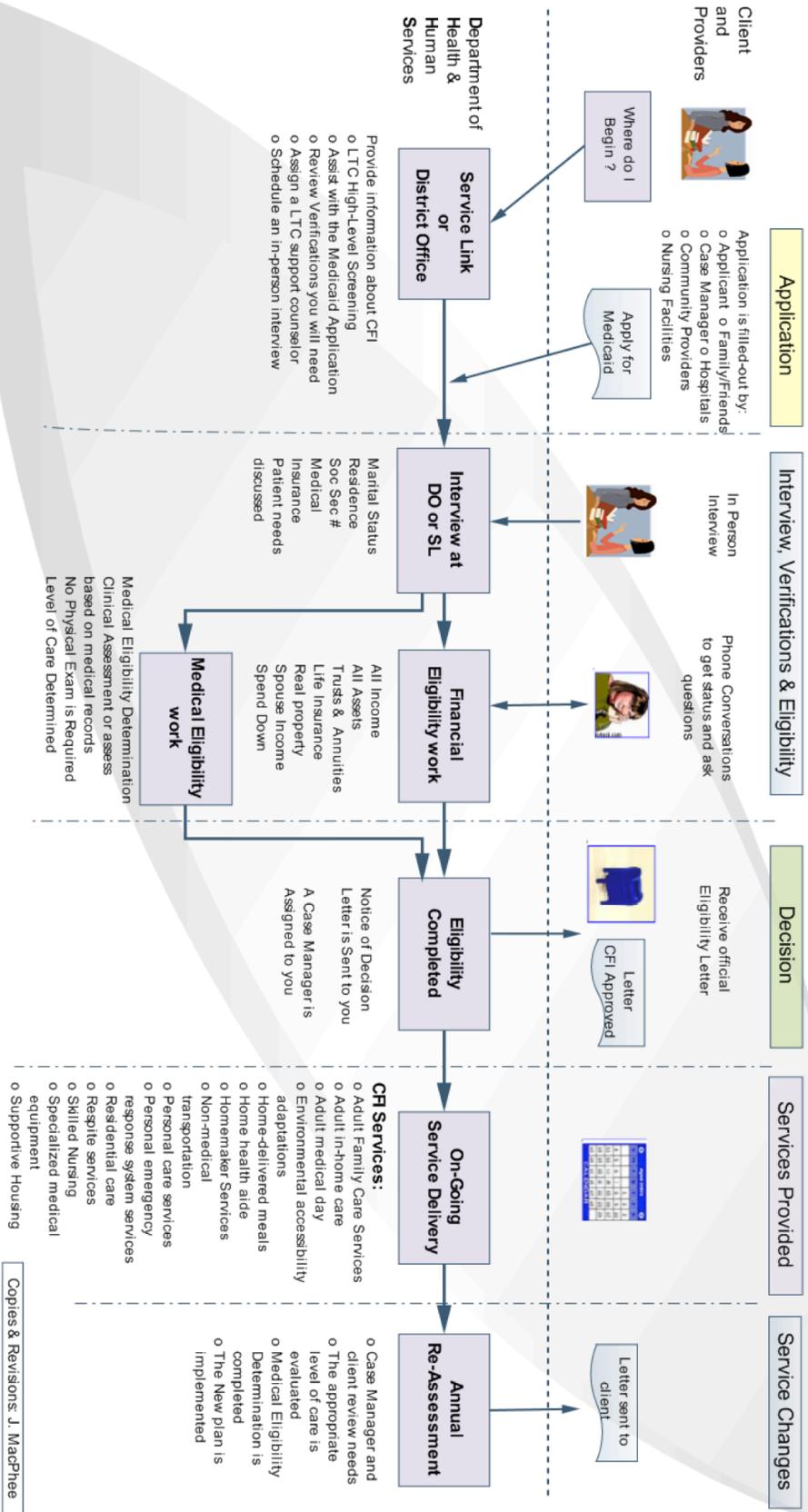
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DHHS LTC - Choices for Independence

Current State Map April, 2012



Appendix 2

Notes from Developmental Disability waiver stakeholder group

2/21/12, Community Bridges, Concord

Feedback

Note: All comments are from work group participants whose confidentiality was assured and whose opinions reflect their own experience. These may not necessarily be indicative of the experience of everyone who receives similar services through the N.H. Department of Health and Human Services.

Opening statement from participants.

“What you have here are parents – those who are very involved and very knowledgeable. We have actively participated to date. We cannot throw away the piece that is working very well. You have everything you need to know – we are very clear and very thorough.”

How do we know that this is a genuine process? This could be perceived as a hoop that we need to jump through for CMS?

We want to be carved out – we want to get rid of the Step 2 deadline, maybe a pilot program to ensure it can be done well. We want to keep our Area Agencies.

If we show you how good this is working – then can we keep our agencies?

Area Agencies are more than just Medicaid.

Area Agencies are already providing care management. Individuals work to a specific budget.

We run the Area Agencies and we are leaders of the Area Agencies. Every change has been family driven – a change risks this being top driven.

History and a direct line to the Commissioner, contact with the Department, levels of bureaucracy fall away.

The philosophy that underpins the Area Agencies this is local control, individualized care. Other states that want to replicate this approach.

Control is more than just veto power. We have been real participants in the care.

Some suggestions:

- Should we talk about the relationship of medical services to in home supports?
- Should we look at replicating this for the CFI population?
- Should we look at the process for accessing in home supports?

Summary Notes From First 2 Sessions with CFI Workgroup

3/8/12 and 3/15/12, TLC, Concord

Note: All comments are from work group participants whose confidentiality was assured and whose opinions reflect their own experience. Theses may not necessarily be indicative of the experience of everyone who receives similar services through the N.H. Department of Health and Human Services.

Currently Working Well

- Service link help is vital
- Flexibility with individual plans
- Choices
- Service and help by some family support specialists at District Offices was very good
- Life Coping is wonderful (case management, Bureau of Elderly and Adult Services)

Challenges/ Problems

- Difficult to get information about services and where to begin
- Access to specialty doctors/ services in NH
- Need more doctors familiar and comfortable with disabilities
- Financial eligibility: experience with more companies and terms
 - Poor customer service skills - uncaring
 - Many obstacles and delays
 - No clear/ explained path - what's next?
 - Credit score trashed - unpaid bills
 - Review of resources taking 90+ days
- Paperwork is lost. Calls not returned
- Cuts to CFI
- Nurses' work ethic
 - LNA - waiting, not responsive, level of care
- Medicaid services
 - Working well
 - Medications, wheelchair
- Communication
- Transportation - must have
- Competition between services- not a choice?
- Life events - marriage, disability, retirement, severance pay- disrupt MEAD eligibility
- Physical therapy
- MEAD - insurance employee paid, part time- lose insurance, asset
- Vocational rehab
- MEAD - only PCA and PCSP
- Get services and still work
- Transportation

- PSP has evolved
- CFI waiver

With Basic Supports

- Advance education (formal)
- Work
- Stay in good health
- Make contributions to society
- People are living longer

Future Needs and Wishes

- Do not place restrictions on provider/ doctor choice
- Education on how MC operates and how to navigate in the system
- Provide case/ choice counselors that are helpful and personal in evaluating needs and matching to plan
- Protect current levels of benefits
- Coordination of care
- Design a delivery system to improve care and gain more from Medicaid spending
- Network to share patient information, HIPPA agreement
- Spend down timing and the day services begin- care
- Safety medically
- Secure personal data
- Financial advisors for individual and family
- Maintain basic values- respect, dignity
- Job shadowing, modeling
- Guardianship for wife, husband, POA
- Limits of vans, limit of available time- transportation
- Vocation training
- Ability to keep working - life events
- Continuous improvement
- Cutover to CM

Step 2 CFI Focus Group Session #3

3/22/12, TLC, Concord

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CFI services that should not be limited:

- Transportation – esp. for medical appointments
- Service stops at 9:00 pm – later than that must pay for out-of pocket
- + evening accompaniment to social functions, classes
- Home-delivered meals
- Availability of in-home nursing services as needed (ex. – help with catheter) not just when scheduled
- Personal care hours – be careful with limits and lack of flexibility
- Skilled staff should conduct assessments and development of service plans
- Evaluations should be conducted in-home if possible (not over the phone)
- Adult day care
- Physical therapy

Numerous comments regarding lack of information available from DHHS (web or staff) and provided by DHHS (staff) about:

- Medicaid and Waiver application steps and status and
- General and specific Medicaid and Waiver services

Don't understand why there are differences between programs and standards for PCAs & PCSPs

Brief discussion about consumers/potential consumers who don't ask about or fully utilize services because "I try to do everything myself"

How do you know who to contact and how do you know where to look when you have questions/need information?

- ServiceLink
- GSIL
- Vocational Rehabilitation
- Hard to identify and make initial contact when interested in applying for assistance

DHHS website – positives & negatives

- Positive – found out who to call
- Negatives
 - MEAD – high-level information – no details (ex. - Administrative rules; unable to apply payment methodology provided and make it match with actual payments)
 - "virtual run-around"

- Couldn't find contact information for case worker
- Not enough tools and information available

Could MEAD recipients be offered Health Care Accounts to set aside tax-deferred or tax-exempt funds for needs?

MEAD recipients should be allowed to protect more resources (ex. keep everything accrued/saved up until time of dismissal or retirement from job)

Exempt assets/resources received through other programs consumer is eligible for (ex. Social Security shouldn't be applied as a resource against Medicaid financial eligibility)

Final comments for Commissioner:

- Focus groups are helpful – keep holding them after implementation of care management
- DHHS & MCOs need to involve consumers more – ongoing involvement about what's working and not working
- Express thanks for assistance received and for how much DHHS does – wants to be more involved in MEAD and employment policy issues
- Paperwork is very burdensome
 - Hard to know what to keep and for how long – some documents back 2 years, some back 6 years
- System is hard to navigate
- Would be nice to be provided with more information on where to go to get information without having to search on your own along with relying on interactions with other consumers/families/agencies
- Want more opportunities to provide input and share experience
- Message board for consumers
- Take time to listen to what people are saying because it will make a difference in their lives



Medicaid Care Management Program Guiding Principles

1. All services will be person/family centered based on an informed-choice, consumer-driven model.
2. Services will be designed to achieve intended outcomes within the context of available financial and human resources.
3. Clients and their caregivers will be educated and informed about their options.
4. The value of services will be measured by health outcomes achieved per dollar spent (cost).
5. All participants within the system, including program administrators, providers, families and clients, will be held accountable to achieve a high level of care through transparent process of continuous evaluation of quality and cost.
6. All participants within the system will be compliant with state and federal laws, regulations and contracts.
7. Culturally competent care will be integrated and coordinated across all systems to achieve the intended physical, behavioral and human service outcomes of all populations.
8. Services will be provided in a fair, equitable and reasonable manner using evidence-based approaches.
9. Stakeholders will be engaged in the design, development and implementation of the system of care.
10. The care management system will be responsible for measuring the impact of services on the Medicaid population as a whole and will continue to improve services to achieve better population health.

— New Hampshire Department of Health and Human Services