



New Hampshire  
Department of Health and Human Services

NH Medicaid Long-Term-Care  
State Innovation Model Design  
Consumer Feedback

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**December 12, 2013**

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*Due to their size, appendices are not included with this report but may be downloaded separately.*

“Thank you for taking the time to ask our opinions. Our state could be a model for the rest of the nation in terms of how to best support our citizens in need.”

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## Background

As part of NH Department of Health and Human Services’ Medicaid Long-Term-Care State Innovation Model stakeholder engagement process, Louis Karno & Company Communications conducted 13 focus groups: 11 with consumers of Medicaid long-term-care services and/or their family members and 2 with agency staff members who work directly with consumers.

The focus groups were invitation-only and were organized in conjunction with local human service agencies that recruited participants for us from among their consumers and clients. Focus groups averaged between 7-10 participants each and we had 92 participants in total.

Medicaid long-term-care consumer groups represented (and number of focus groups conducted):

- People with physical disabilities (1)
- Parents of children with chronic/severe behavioral health issues (1)
- Adults with behavioral health issues (4)
- Families of people with developmental disabilities (2)
- Adult children with elderly parents who need long-term care assistance (3)
- ServiceLink staff members who counsel adult children with elderly parents (1)
- Direct support professionals who work with people with developmental disabilities (1)

Focus group sessions were an hour-and-a-half to two hours long. We begin with a short presentation about the Medicaid program, long-term-care services and the goals of the State Innovation Model project.

We then showed the group a simplified diagram of the model, walked them through it and then conducted a facilitated discussion based on a set of questions in a discussion guide developed to elicit feedback on the proposed model.

In addition to the consumer focus groups, we also conducted a 35-question online survey. The survey was developed using feedback from the focus groups and from the project's Education and Outreach stakeholder workgroup. Survey participants were recruited by email through the SIM model design stakeholder network. We had 892 survey participants with 576 completed surveys.

- 6% of survey participants identified themselves as people who currently use the NH Medicaid Long-Term-Care System
- 53% are family members, caregivers or guardians of those who use the system
- 19% provide services to those who use the system
- 22% don't use or provide services but are interested in how the system operates.

We provided regular updates on consumer feedback to the consulting team from Deloitte managing the project for the Department, to the Education and Outreach Workgroup and to the full project stakeholder group at its meetings.

*All direct quotes used in this report are from focus group participants or survey respondents whose confidentiality was assured.*

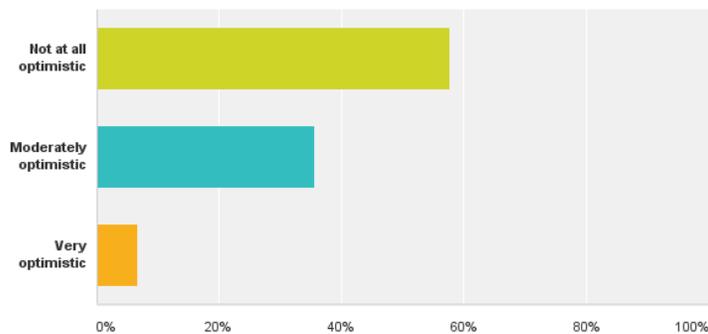
## Reaction to the model

With the exception of members of the two focus groups representing those who are served by the Developmental Disability system (who said they were against transitioning to care management, or change to the current long-term care service system) **the state innovation model as proposed looks good to people who participated in the focus groups and it makes sense to them.**

A survey question we asked to gauge perspective on change to the current service system illustrates the divergent views on the proposed system redesign. The graphs below are cross tabulations of survey respondents who are: a) served by the Developmental Disability System (top); and b) who represent other long-term-care populations: the elderly, people with physical disabilities, acquired brain disorders and behavioral health needs (bottom).

**Q32 How optimistic are you that a redesigned Medicaid long-term-care system will be an improvement over the current service system that you use?**

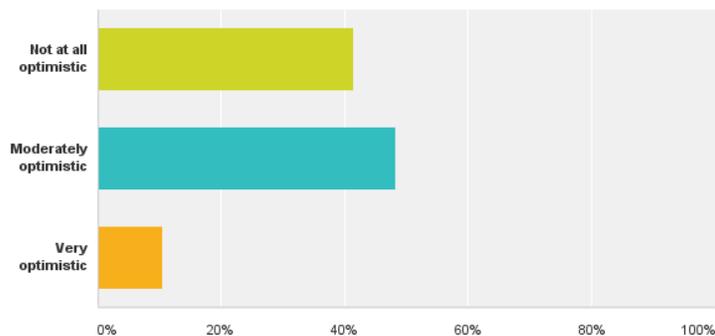
Answered: 371 Skipped: 90



View of those served by the Developmental Disability System

**Q32 How optimistic are you that a redesigned Medicaid long-term-care system will be an improvement over the current service system that you use?**

Answered: 297 Skipped: 113



View of other Medicaid Long-Term-Care populations

## Adverse reaction to references to health

In one group, Developmental Disability stakeholders became angry at the references to "health" originally used in the model. They said it means that we are coming at this from a "medical" model, which to them means, "This system thinks our children are broken and can be fixed."

This reaction appears to stem from this group's resistance to the transition to Medicaid care management. As one participant said, "How is a for-profit insurance company which has (in her view) no experience in working with people with developmental disabilities going to treat our kids? They'll just do what they know, which is the acute care model – which is absolutely the wrong approach for us."

## They want to keep what works for them

Both the Developmental Disability System and the MEAD (Medicaid for Employed Adults with disabilities) program were identified as being successful by those who use them, and **many focus group participants expressed the hope that the new system wouldn't dismantle what works well in the current model, but would bring the rest of it up to the level of these programs.**

## Huge room for improvement

Other than the Developmental Disability system, from the Medicaid consumer perspective there seems to be **great deal of fragmentation, system silos and lack of guidance that people think the model, as proposed, could improve.**

It was particularly heart wrenching to listen to parents of young adults (transition age) who appear to be nearly on their own in fighting for their child's needs and facing a situation in which few services are available to help their kids.

From this group's perspective, care coordinators and counselors come and go too often. Their children are often not perceived by the school system or legal system to have chronic care needs because they "look like everyone else and often appear to be high functioning."

“The system makes it twice as hard to keep a person at home than it does to put them in a nursing home.”

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## Eligibility

The eligibility process surfaced as a problem for one consumer group in particular.

Adult children with elderly parents appear to find the Medicaid system a confusing maze. **These consumers typically have no prior knowledge of the human service system or government programs.** Several told us that they found out about the ServiceLink program, for example, purely by chance and without the help they received from ServiceLink counselors they would have been effectively shut out of the services that their loved ones need.

These consumers said that something needs to be done to **make people aware that help is available through Medicaid and other human service programs** prior the eligibility step. It appears that that once they are eligible for Medicaid they need a “guider” to help them navigate the system. This “guider” might be the team coordinator in the proposed model or it might be a ServiceLink staff member or case manager with an organization they work with.

Many of these stakeholders find the Medicaid eligibility process daunting and burdensome. They understand that there needs to be protection against fraud, however they find the eligibility paperwork and documentation a barrier to helping those who need help. They suggested shortening the current 5-year eligibility look-back period to 3 years.

Even medical eligibility for this population is cumbersome. According to participants in one group, it takes 45 days to 2 months to receive an in-home medical eligibility assessment by a nurse. They said that it is easier to place a loved one in a nursing home (which they said will perform the medical eligibility assessment in a day and work with Medicaid so that they can receive “back-payment” for services provided while awaiting financial eligibility determination).

If the goal is to keep people in their own homes, they asked, why can’t the system send a nurse out to a person’s home sooner, and “back-pay” for services being provided by home care agencies too?

“When you talk about the Life Plan I think of the term ‘purposeful living.’ You can get trapped when there is no means to an end. Purposeful living gives you back hope, which is a huge void for people.”

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### **Eligibility assessment, life planning, team coordination approach**

People in the focus groups liked the concept of assessing and addressing **wants and values** as well as needs.

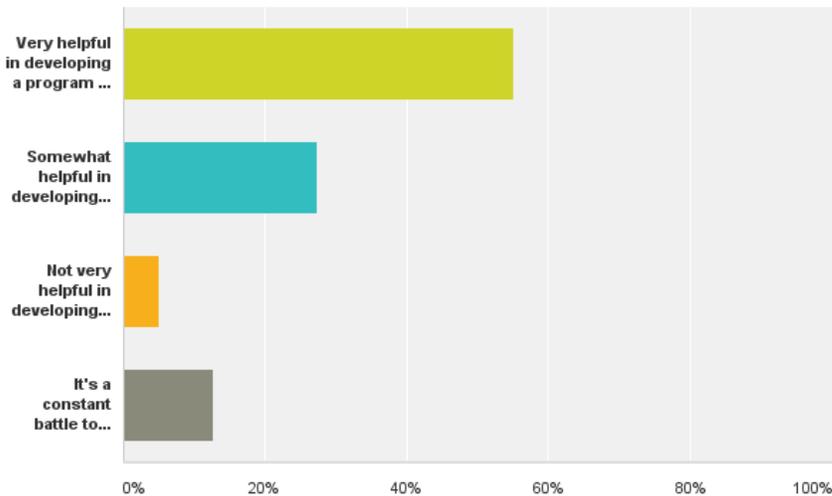
Behavioral health consumers raised the point **that a “Crisis Plan” must be a part of the Life Plan** and that **allowances should be made to update or change the Life Plan continually** because their kids cycle through changes on a near daily basis.

**The concept of a coordinated team approach with a service plan and budget are appealing.** Many people in the groups have had experience with similar models, either in school with children with special needs (family and child's team develops IEP, service plan or wraparound plan) or in the NH Developmental Disability system, and are comfortable with it.

- 80% of survey respondents have had experience with a plan.
- 77% said they had developed it in consultation with school or agency staff members, a case manager or other professionals.
- 25% said they took the lead in developing the plan.
- 55% of those who had experience with a team said that it was “very helpful in developing a program of services and supports to meet my (our) needs.”

**Q14 What statement comes closest to your general experience with these teams of service providers?**

Answered: 433 Skipped: 459



Focus group participants liked the concept of a team and "Team Coordinator" function as it indicates that someone has responsibility for making things happen, as long as everyone on the team, including the individual or family, has equal weight and that decisions will be made by consensus rather than decree. **They view the role and expertise of the Team Coordinator as absolutely crucial to the success of the whole model.**

In terms of the most desirable qualities that a team leader or service coordinator possess, survey respondents cited:

- Is experienced and knows how the system works – 79%
- Listens to me (us) – 76%
- Is someone I (we) can meet with face-to-face – 74%

The option of offering life planning to people before they become eligible for Medicaid was viewed very positively. Children of older adults with dementia or other memory impacting disorders, for example, suggested the “earlier the better.” This would address one of the biggest challenges for this consumer group. They know they need help, but don’t know what help to ask for because they have absolutely no insight into what help might be available to them or their loved one.

“Working out in the InShape program is like therapy. I get a lot out of it. Maybe more than sitting down and talking with someone.”

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## Wellness incentives

The concept of wellness incentives was generally well received, however the question of the appropriate match between incentives and the legitimate ability of people to accomplish them came up several times. People said that, to be fair, **incentives should be within the reach of the individual consumer.**

Health activities most often mentioned as worthy of incentives included nutrition and exercise programs.

## Encouraging people to be shrewd consumers

Want to incent people to be good consumers and shop responsibly for services? The most common suggestion among participants in our focus groups was to **let them see the bills that Medicaid pays on their behalf. They apparently don't get a copy of the bills or an explanation of benefits now.**

What do consumers want to know to help them select a good provider?

- First, a list of who is available.
- Second, their background and credentials.
- Most important though is the flexibility to switch providers when and if they want to.

**Consumers said that satisfaction with a provider is largely a matter of chemistry or fit.** This means it's largely a matter of trial and error, so if they don't click with a provider, they'd like the flexibility to try a new one.

“The most important thing for a person is a provider who is trained, competent and well paid. That’s what leads to quality of services and quality of life for that person.”

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## Workforce quality

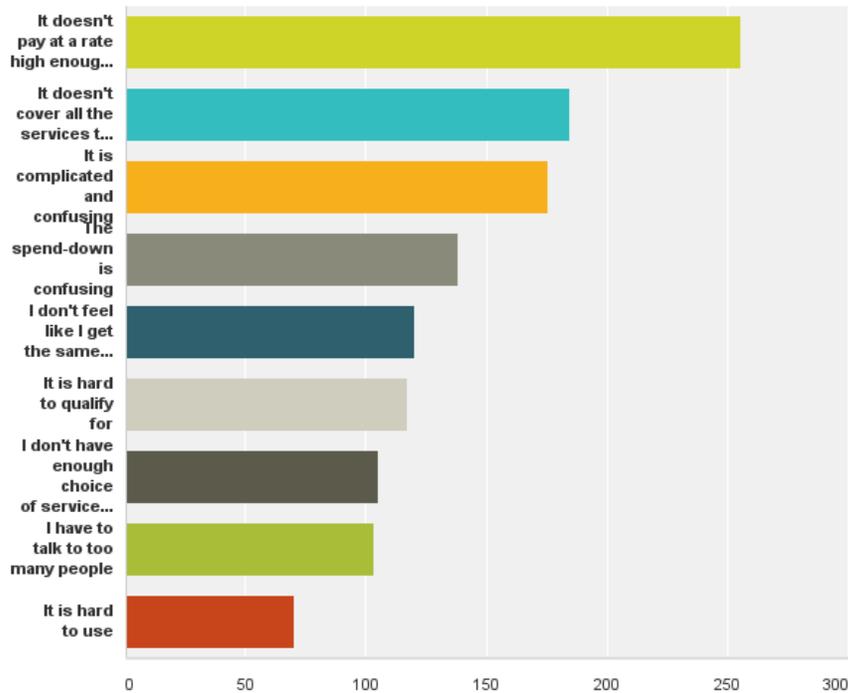
**Workforce issues came up in nearly every focus group.** We heard that most direct support and home care providers receive little training and are poorly compensated. This results in high turnover, which means that the consumer’s progress reboots with each new care provider. Turnover of agency case managers due to high performance expectations and poor compensation was also cited as problematic. We heard several times, “Every time I get a new case manager I have to start over.”

We heard from direct support staff and others in focus groups that **the role of direct support is undervalued in the current system and as a result consumer outcomes are not what they could or should be.** They said that those who work with consumers on a daily basis are the foundation of the long-term-care system, and that improving training and compensation should be features of a system redesign in order to improve consumer satisfaction and outcomes.

We were told that this undervaluing illustrates “deviancy image juxtaposition.” Society doesn’t recognize the value in someone with a disability or an elder because they are consumers not producers. The person in society isn’t seen as valuable and the person who works with them isn’t either.

### Q11 What don't you like about the current NH Medicaid Long-Term-Care program? (Choose all that apply)

Answered: 481 Skipped: 420



However, **system consumers appear to recognize the value of good service providers.** As illustrated above, when asked what they didn't like about the current Medicaid long-term-care system, the leading response among survey respondents (53%) was, "It doesn't pay at a rate high enough to keep good personal care attendants or direct support providers."

### Greater breadth of services needed

**Focus group participants in the northern part of the state said there was a great need for professional services and specialists closer to them.** They frequently drive 90 minutes or more to southern New Hampshire to access care for their children.

While other consumer groups, e.g. those with developmental or physical disabilities or the elderly, discussed wanting to remain in their homes or in their community. Parents of young adults with behavioral health issues see small institutions, (essentially assisted living facilities for people with behavioral health needs) as a highly desired alternative to homelessness, providing peer support and safety.

# “Choice, choice, choice and more choice – with adequate funding.”

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Housing also came up as a need in other focus groups representing other behavioral health consumers and the elderly.

Interestingly, when asked what they find difficult about managing a services account (if they had one) or they thought would be difficult if they were to have one, survey respondents' top responses were:

- Finding quality services – 42%
- Finding the needed services – 39%
- Finding affordable services – 35%

## **Paperwork is not the best indicator of service quality**

We heard in several focus groups that current system quality measures and payment tend to focus on completed paperwork and not on consumer outcomes. Focus group members suggested that the new system extend evaluation to consumer outcomes rather than system inputs. For example, having consumers sign off on their Life Plans and compensating an organization for that is not as strong a measure of quality as consumers actually accomplishing the goals in their plans.

We also heard that the goal of the long-term-care system should not be custodial. “We need to help people stay at home, get jobs, make friends, have dates,” a member of one group said. “Most people’s relationship circles are only with staff and family. No one measures relationships.”

## **The role of the advocate**

We heard that while a care team could be a positive experience, it could also be intimidating for many consumers. “Sometimes these meetings can be uncomfortable,” said one consumer. “They try to put words in your mouth or try to have you set goals that they think you should set. You see things differently than what they are saying and you have a room full of professionals that are telling you what you need to do.”

“Please think and act as though you were trying to make things better, easier, more beneficial for your own family member. Thank you for all your hard work on behalf of families in New Hampshire with significant challenges!”

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The solution, we heard, is to have someone attend these meetings with the consumer as their advocate. It could be a family member, a friend, or a direct support worker – in short, the person who knows the consumer best and can help present their viewpoint. As it relates to this model, this person could be the individual’s Team Coordinator.

### Show us the money

Although the reaction to the proposed model was highly positive at some point in most groups, someone raised the point that in theory this was a great idea, but **without enough money behind it, the model can’t deliver on its promise.**

To address this concern, we suggest that thought be given to **building in a meaningful feedback loop to policy and budget makers that demonstrate the value and cost effectiveness** of the new long-term care system and services it delivers. Otherwise, the primary feedback mechanism to those who control the purse strings is the state budget process -- which tends to focus on cost and not on value.

### Base the design on art, not science

A common theme with Medicaid consumers is that **every person or family's situation is distinctly different.**

The long term care service system has to be designed to accommodate and deliver on a nearly infinite variety of life plans designed to accommodate a nearly infinite variety of needs, wants and values. To be successful in meeting the needs of consumers the system really needs to be based on art, not science. As one mom said, "I want my kid's plan to be based on her needs, not her diagnosis."