

# **OREGON MEDICARE-MEDICAID LISTENING GROUPS FINAL REPORT**

## **INTRODUCTION**

In support of its Design Contract to Integrate Care for Dual Eligible Individuals (“Design Contract”), the Oregon Health Authority (OHA) held five listening groups during the week of December 12, 2011 designed to solicit input from individuals dually eligible for both Medicare and Medicaid (“individuals who are dually eligible”). The purpose of the groups was to solicit input on OHA’s Design Contract proposal from those individuals who would be directly impacted. Listening groups were held in the cities of Portland, Eugene, Bend, Roseburg and Coos Bay. Alice Lind from the Center for Health Care Strategies facilitated all of the groups.

## **METHODOLOGY**

The five communities were targeted because they represent statewide geographical diversity and are among the areas with the largest population of individuals who are dually eligible. These communities have also been identified as likely to have some of the first coordinated care organizations (CCOs) who will be responsible for integrating care and services.

To recruit participants, OHA mailed personal invitations to approximately 100 individuals who are dually eligible in each chosen community. OHA also engaged partner organizations, including AARP, health plans, local Senior and People with Disabilities and Area Agency on Aging offices, and local federally qualified health centers. Twenty-one individuals participated in the listening groups, including sixteen individuals who are dually eligible and five caregivers of individuals who are dually eligible. Thirteen of the participants were women, eight were men.

## **THE DISCUSSION GUIDE**

OHA staff developed questions designed to get feedback on several key concepts and recommendations that came out of the Health System Transformation process, including the Medicare-Medicaid Integration of Care and Services Work Group (Work Group). The 30-member Work Group met from August through November and included consumers, providers, health plans and other stakeholders.

After gaining some background on participants' experiences with the health care system, they were then asked share their thoughts on five key concepts:

1. Person-Centered Care
2. Individual Care Plans
3. Interdisciplinary Care Teams
4. Health Care Coordinators and Other New Roles
5. Accountability

## **SUMMARY OF KEY THEMES**

Participants contributed many insights that support both OHA's and the Legislative Assembly's vision of Health System Transformation. In general, participants supported the following elements reflected in the five key concepts they were asked to consider:

- Making care more person-centered through improved communication and consideration of individual's unique needs;
- Individualized care plans including participation by individuals in defining goals;
- Improved communication between providers of all types;
- Strong support for new roles (health care coordinators and health system navigators in particular) that would emphasize a personal connection between the individual and the health care system and include an advocacy component; and
- Both personal and system accountability for improving health.

## **EXPERIENCES OF CARE**

As an introduction to the listening groups, participants were asked to share their experiences with the health care system, both positive and negative. Questions were asked to gain insight on participants' experiences of provider communication, hospitals and emergency departments, and care coordination.

Most participants expressed satisfaction with their individual providers and thought their providers were doing a good job of providing care and communicating with each other. Participants with in-home caregivers or family members who assisted in their care were grateful for the assistance those individuals provided.

“Caregivers are the backbone of the system...without [my caregiver] I would be dead.”

These participants noted that this support allowed them to continue to live at home and avoid more costly care. (Of note, several participants had greatly limited mobility and one was ventilator-dependent.) Two participants with caregivers expressed concern that the number of hours their caregiver is available is limited and the compensation paid to those caregivers may be inadequate.

Among the areas of dissatisfaction, the most common complaint was the coverage of, and access to, certain services and supplies through the Oregon Health Plan. Participants expressed almost unanimous dissatisfaction with the coverage of vision and dental health services, as well as coverage of DME. Complaints about denied services were sometimes related to concerns that these services could have prevented the need for more expensive treatment in the future. Additionally, lack of after-hours clinical care resulted in emergency room care at much more expensive rates. Participants varied on their satisfaction with the coverage of prescription drugs. Several participants were grateful for the prescription drugs they were receiving. Other participants expressed frustration that certain medications were not covered.

Several participants had encountered barriers in accessing mental health care services. In some cases these barriers resulted in the person giving up on trying to obtain the mental health care they needed.

“The first thing [the mental health provider] said to me is ‘Oh, you’re on Medicare, I’m not supposed to see you...’ There was no way I could discuss a problem with her...I was so rattled...I never came back.”

Other participants expressed frustration at being limited in the number of visits they could have to their mental health provider. Participants who had disengaged from the mental health system managed their mental health prescription drug needs through physical health providers such as their primary care physician or orthopedist.

While most participants had positive experiences with their care providers, participants who indicated they were enrolled in managed care organizations (MCOs) varied on their level of satisfaction with these organizations.

“There are things like suction catheters for his airway. Recently they were cut down to three a day...so we have been struggling...It is increasing his risk of infection which causes things like a risk of hospitalization.”  
(Caregiver)

Common areas of dissatisfaction included concerns that MCO rules acted as barriers to care. Participants also mentioned poor communications, especially written materials that were unclear and not person-centered.

“Speak to me in Mom-eeze. As a caregiver, how can I make sure they understand the steps...if nothing else [we need], training for caregivers and family.”  
(Caregiver)

Several participants shared negative experiences with hospitals, especially emergency departments. Some indicated that their primary care provider had not been notified of a hospital admission. The participants with limited mobility or who were ventilator-dependent felt that hospital staff were not equipped to deal with their individual needs. One of these participants noted a regulatory barrier that prohibits him from having his caregiver present during hospital visits. One participant noted a prescription error that resulted after a hospital discharge.

## **1. PERSON-CENTERED CARE**

Participants were asked whether they thought the health care system is currently person-centered. Participants were also asked whether they would value a person-centered system and what could be done to get the system to be more person-centered.

Most participants felt that the current health care system is not person-centered enough. Several participants expressed that they thought the system “pigeon-holes” people and does not do a good job of considering people’s individual needs. Several participants cited examples of recent cuts to needed durable medical equipment or medical supplies. These participants thought

that the system should do a better job of considering the individual's unique situation and not just categorize them by health condition.

“I am on a ventilator and I am a larger guy...Getting the right stuff (is important)...Each case needs to be taken separately and not one rule for everybody.”

Participants felt that the current health care system does not do a good job of considering needs outside of immediate medical care, including social needs. Participants with provider access issues faced the burden and challenge of utilizing non-local providers. One participant raised the desire for the health care system to do a better job of considering a person's faith. In discussing disconnections between the health care system and the individual, participants felt that the system was difficult to navigate and that information regarding benefits and coverage was not often accessible.

“I think the reason we're having problems with our health care system...is that it is not a person-centered model, it's a medical model. It is like turning out a product and not...taking care of the individual as a whole...we need full-person care.”

Participants universally liked the idea of making care more person-centered. They noted that more person-centered care would assist individuals to be more involved and active in their care. Participants thought that good person-centered care would involve better listening from the health care system. They felt the system could do a better job of humanizing and personalizing communications to service recipients.

Those participants who felt their care was person-centered were very satisfied. This satisfaction was tied to a feeling that their providers cared for them as an individual.

“I have cancer and the team is tremendous...My friends were amazed with how well everything was coordinated. Everything went like clockwork.”

## **2. INDIVIDUALIZED CARE PLANS**

Participants were asked whether they currently had a care plan developed in consultation with their primary care physician or care team. Participants who indicated they had a care plan

were asked about their experience. Participants who indicated that they did not have a care plan were asked if they thought it would be helpful.

Most participants with a care plan felt that they did not participate in its development. Those that did participate in developing their plan had very positive experiences. One participant shared her experience with developing a care plan with her nurse advocate. She said that they review the plan every week and her nurse advocate follows up on the goals outlined in her plan. Her story elicited responses of, “I want that” from several of her peers in the group.

Participants who did not have a care plan were receptive to the idea of participating in the development of one. Participants commonly tied the notion of a care plan to improving the person-centeredness of their care.

“Instead of things being so compartmentalized...we need individualized care for our main health problems...with preventative care.”

### **3. INTERDISCIPLINARY CARE TEAMS**

Participants were asked about their experiences with the people involved in their health and other care needs, including primary care providers, specialists, mental health providers and case managers. Participants were asked if they thought that these individuals did a good job of communicating with each other to coordinate the participants’ care needs.

Nearly all participants had multiple providers involved in their care, including primary care providers and specialists. Several participants had experience with mental or behavioral health providers. As Oregon Health Plan beneficiaries, all participants have a case manager that helps with eligibility and social service needs. Participants shared mixed feelings about whether they thought their care was well coordinated. Provider communication played a key role in participants’ perception of how well their care was coordinated; those who felt their care was well coordinated noted consistent communication between their various providers, while those who felt their care was not coordinated perceived a lack of communication.

Participants who used family practice or multi-specialty clinics felt very satisfied with the level of coordination between their providers. These participants noted test results were quickly made available to all their providers. These participants also found that their prescription

medications were well coordinated amongst prescribers. One participant who felt her care was well coordinated said that prior to coordination she would utilize the emergency department to deal with her asthma. Several were aware of the impact that a system-wide electronic health record made to effective care coordination.

“I have several doctors...CAT scans, x-rays, they just pull right up. The technology has made a huge difference in tests not being ordered twice...and medication interactions being avoided.”

Participants with experience with mental or behavioral health systems commonly noted a lack of coordination between those providers and their physical health providers. One person commented that this lack of coordination left her feeling that she had no place to go once her mental health episode of care ended. Participants noted the interrelation between one’s physical and mental health and said that lack of coordination between the systems can negatively impact both physical and mental health.

As noted above, several participants felt that there was not good coordination between hospitals and their primary care providers. They commented that this made them feel responsible for coordinating with their primary care provider after a hospitalization or emergency department visit.

“There is real lack of communication between our local hospital and our doctors...getting the doctor the emergency information. They just assume the client is going to tell their doctor that such-and-such happened...as we get older and are broken and are falling apart we don’t always remember to mention that these things have occurred, we just assumed that our doctor has been communicated with by our hospital.”

#### **4. HEALTH CARE COORDINATORS AND OTHER NEW ROLES**

Participants were asked to react to the concept of having a single point of contact within the health care system that could help coordinate care. Participants were also asked about the qualities they would want this person to have. Participants were asked to react to three potentially new roles within a better-coordinated health care system: (a) personal health

navigator; (b) peer wellness specialist; and (c) community health worker. Participants were asked about how they would want to interact with the individuals filling these roles.

**Health Care Coordinators:** Participants were almost universally supportive of the idea of a health care coordinator within the health care system. They were very receptive to the idea of this person serving as a single point-of-contact that could help them navigate the health care system and could be contacted when health care issues or questions arise. Most participants felt very strongly that a health care coordinator should serve a patient-advocate function.

“There needs to be a component of the health care system where people can have an advocate as they need it, to speak for them.”

Participants felt that in order to be successful, a care coordinator would need to be knowledgeable of all of the components of the physical, mental and social systems. Participants responded positively to the “personal touch” that a care coordinator could provide. They thought that to be valuable, the care coordinator should be a good listener, patient, empathetic and respectful. A couple of participants felt that this person should be non-clinical.

While generally supportive of the concept of a health care coordinator, some participants did raise concerns. One concern raised by multiple participants was the potential caseload coordinators would be asked to take on. Participants noted the burdensome caseload that their case managers have as something that could reduce the effectiveness of a care coordinator. Participants were open to the idea that the case managers should prioritize their caseload to the highest priority or most acute members, and some expressed that they were “basically healthy” and not in need of constant monitoring.

“I don’t expect that person to call me once a month to see how I’m doing. I don’t need that.”

One participant expressed concerns about whether this role could be effectively filled by just one person. Another participant worried about coordinator availability and potential transitions between care coordinators and raised the idea of a two- to three-person team approach to care coordination.

**Other New Roles:** Participants were generally receptive to the roles of personal health navigator, peer wellness specialist and community health worker. Participants responded

positively to the idea of a navigator that could remind them of upcoming appointments and follow-up on treatment plans. Participants also liked the idea of a peer wellness specialist. Participants with mental and behavioral health experiences especially liked the idea of this role as someone that could be utilized after or between episodes of care (e.g. to lead group meetings).

“We’ve all heard of coaches that coach professional people. If there was somebody like that to go to, it would have been good.”

A common notion raised by participants was using these new roles to increase education to the individual. In particular, these roles could serve to educate individuals about their care options and help them reach their individual health goals. Several participants believed increased education would empower them to be more involved and active in their care.

“If there was someone I could go beyond with the things [my doctor] said, then maybe I could help myself more.”

## 5. ACCOUNTABILITY

Participants were asked to suggest ways that the state would be able to tell if the health care system was improving or maintaining a person’s health.

**Personal Accountability:** In three of the listening groups, participants raised the idea of individual accountability. They felt that if they were better educated and given support in the health and social systems, they could be more proactive and accountable for their overall health. Participants noted that it is the individual’s responsibility to listen to their providers and follow through when given direction.

**System Accountability:** In two groups, participants offered specific, detailed input on how the state would know if the health care system is improving or maintaining an individual’s health. Examples were: lower utilization of crisis care and emergency room; increased wellness and use of mental health; improved coverage and formulary.

To hold the system accountable for the goals of Health System Transformation, participants raised the notion that the state needs to ask beneficiaries directly about their experiences to find out whether system changes are helping. When asked specifically about

health care surveys, participants were largely supportive of this idea and preferred that the survey be conducted in person or over the phone rather than by mail.

“I was much more willing to come here [to the listening group], knowing that I was going to have an opportunity to talk about it, rather than filling out a questionnaire... Having somebody to talk to is much better than asking people to fill out a questionnaire that they might not feel related to the problem.”

### **ADDITIONAL COMMENTS**

- Several participants felt very strongly that any change to their system of care needs to be transparent.

“Every level from the very lowest to the very highest of this change should be constantly assessed and... it should be very transparent...Members, nurses, doctors, phone receptionists, direct home care workers, insurance companies... There’s going to be bumps in the road ...and the only way to effectively get through them is to be aware of that ... We all have to come together and ... assess and address each one of those things that come up...and figure out real solutions”  
(Caregiver)

- A few participants expressed anxiety about any change that might have an impact on their current set of services or providers. Participants felt strongly that any system change should not result in them having to change providers.

“I had a friend who wanted me to ask if she should stock up on her prescriptions in case this change takes them away from her.”

- Several participants would like to see more consumer voices involved in the operations of the health care system, in line with the Consumer Advisory Council envisioned in House Bill 3650 (2011).

- Several participants noted that they were willing to use lower cost alternatives to treatment (e.g acupuncture instead of surgery) if these services were covered by the Oregon Health Plan.