

Colorado Demonstration Project Focus Group Summary Report

FOR THE COLORADO DEPARTMENT OF HEALTH CARE POLICY AND FINANCING

Overview

Center for Health Literacy researchers conducted a series of focus groups in January and February at the Department of Health Care Policy and Financing's request. The goals of the focus groups were to assess client, caregiver, provider, and advocate satisfaction with the current information in use now, and to identify participants' preferred methods of receiving communications about the Demonstration Project.

The first group took place on January 22, 2013, at the Alzheimer's Association, 455 Sherman Street, Denver, Colorado. Seven people participated: six caregivers and one advocate. Participants ranged in age from 35 to approximately 81. Four of the caregivers worked full time; the other two were retired.

The second focus group took place on January 24, 2013, at the Mile High Independent Living Center, 110 16th Street, Denver, Colorado. Ten people participated; nine clients and one caregiver.

The third focus group took place on February 7, 2013, at the Office of Youth Development/ Parks Recreation & Open Space In Aurora, CO. The group was moderated in Spanish, and all of the participants were native Spanish speakers. Five people participated; three clients and two caregivers.

The fourth focus group took place on February 12, 2013, at the Multiple Sclerosis Society, 900 South Broadway, Denver, Colorado. The group was made up of nine Medicare-Medicaid Enrollee Advisory Subcommittee members and one caregiver who was not a member. Seven people were present in the room and two others participated by phone.

Summary of findings

1. Clients, providers, advocates, and caregivers felt they need more trustworthy sources of information.
2. They also expressed a need for information that is written clearly. They want to be able to rely on enrollment materials for information, and to do that they have to be able to understand them easily.
3. Spanish focus group participants wanted more information available in easy-to-read Spanish.
4. The focus group participants were optimistic about what the Demonstration Project might do for them in terms of improving services. Their concerns focused on the most obvious things: Will they be able to keep the providers they have now? Will the Demonstration Project cost them anything? Will they have to fill out more paperwork? Will they be able to contribute in a meaningful way to the decisions made by their care team?

Moderators' observations:

In answering questions and in general discussion, participants expressed a good amount of confusion about what services they or the person they care for might be entitled to, how to find that out and how to access those services. While most participants were polite and friendly, they revealed deep frustrations about the “hoops” they feel they have to go through to get information that they trust.

Recommendations

The moderators recommend the following:

1. Make enrollment materials as clear and uncomplicated as possible, so that enrollees can understand them without struggling.
2. Offer more or improved training about benefits and services to service organizations and other caregiving groups, so that they better understand the information they are disseminating.
 - Webinars, interactive Question & Answer sessions, and other online training might be the most cost effective methods to use. (Clients often do their own search for information, and would also benefit.)
 - Upgrade the Department’s website so that it becomes easier to navigate, easier to read and understand, and more usable and welcoming to clients. Keep it fresh, and include posting dates at the bottom of screens, so that clients learn which pages contain the most current information.
 - Provide an email feature on the website, so that stakeholders can write questions (in English and Spanish) and expect an accurate answer within a prescribed period of time.
 - Provide a chat feature on the website so that stakeholders can ask questions at designated times. This feature should also be in Spanish.
3. Improve marketing strategies to promote services. Consider PSAs on radio and television, so that people who are just beginning to experience problems will know that there is help available. Include Spanish radio and television stations.
4. Publish all informational materials—in print or on the website—in Spanish. Make sure the translation is adapted for the literacy level most appropriate for the target audience.

What did the participants say?

THE CLIENTS

“I don’t understand the paperwork. I read it and tell them to send it to me in Spanish, if that makes a difference. It makes no difference at all. It’s very complicated—the terms that they use. . . We need some kind of training or more understandable paperwork like when somebody comes in to my office, then I could just explain.” *Staff member from the host facility*

“I feel like they sort of purposefully make it difficult; like you said they deny people looking for coverage—we’ve heard that from our families too. They don’t make the information easy to access and they don’t staff phone lines where you can ask questions.” *Provider*

THE CAREGIVERS

“Last year—about a year ago—I put [my wife] in a nursing home because I could no longer handle her by myself. But as far as Medicare and Medicaid, my opinion is they need to get down to about eight to tenth grade where the average person can understand what’s being said.” *Caregiver*

“My mom—I had to sign her up for Medicaid. She just passed away, and even the ending of it was not fun, trying to figure out what was paid and not paid. Trying to maneuver on the website to figure it out! . . . I tell you I’m “legalesed” up to here.” *Caregiver*

“My mother is 91 (soon to be 92) and I’ve been taking care of her since 1995, so it’s been a long time. Of course I’ve taken care of all of the paperwork. I work in this business—I am a social worker—and still it was a total nightmare.” *Caregiver*

“My father, he’s medical, Medicare. He’s with my mom and she’s not very computer literate. It’s tough for her, by her not being able to keep up with the paperwork. I want to know how I can help. But I don’t even know where to start.” *Caregiver*

MEMBERS OF THE SUBCOMMITTEE

“A lot of my experience is as an advocate for my clients; helping them figure out what Medicare pays for what Medicaid pays for, how to access those services. We need a more simplified system and I was hoping that this demonstration would really help with that.” *Provider*

Whom do focus group participants trust to give them accurate information?

THE CLIENTS

“Not Social Services. They give me nothing but misinformation as far as I know—they are a source of misinformation.” *Client*

“It is hard, because the government can give you 20 million answers to one question—anybody that you speak to.” *Client*

“I don’t trust any of these people because I never get the same story when I call. It’s always a different story.” *Client*

“I don’t trust them either. They have it where they have this number that you call so you don’t have to talk to a person and by the time you push these buttons and be on hold you done forgot what you were talking about.” *Client*

“Social Security is the . . . one that really tells you the truth. Medicaid and Medicare—they cover whatever they want.” *Client*

“Social Security is alright—they’re not too brilliant but they give you consistent answers. Social Services, like I said, is a disaster. CO Legal services is my top trusted source. The Cross Disability Coalition is my second. Some of my clinicians are third.” *Client*

THE CAREGIVERS

These are trusted sources of accurate information:

- » All would trust information disseminated by doctors, clinics, and hospitals.
- » Three would trust print information if they could understand it.
- » Three would trust information distributed by government agencies.

THE SPANISH-SPEAKING PARTICIPANTS

These are trusted sources of accurate information:

- » Letters and notices from government sources
- » Information I get by phone
- » Information I get at the clinic

Where do focus group participants get information now?

MEMBERS OF THE SUBCOMMITTEE

“I get information through seminars, legal classes, and attorneys on the Board of directors, much trial and error and a lot of word of mouth.” *Provider*

“Going to the state website—it’s really hard to get any specific information.” *Client*

“I usually make a phone call to Medicaid or Medicare. And then I don’t get very much information from them, and they don’t know what they’re doing.” *Client*

“I would say the community; I’ve been around long enough that I know who to ask. And also word of mouth.” *Client*

“I’m more on the provider side; in the last 25 years that I’ve been doing this it has become incredibly more complicated all the time. I’m not sure it’s saving money for anybody. Instead of filling out one page on one side you have to fill out 50 pages. I’ve also had real difficulty trying to get information through people on the phone lines; a lot of people have just started and know less about it than I do.” *Provider/client*

“My “go to” place is online; I go right to the Medicare and You Handbook first, because it’s written in a fairly simple way and it’s easy to understand and it provides links to more in depth.” *Caregiver/advocate*

THE SPANISH-SPEAKING PARTICIPANTS

- » Two call 800 numbers (with Spanish).
- » One gets information through a PCP and a hospital.
- » A bilingual caregiver uses the internet.
- » A second bilingual caregiver reads information sent by mail, in English.

Both bilingual caregivers reported they did not know they could request written materials in Spanish, and one of them added, “This could be better for my father. In this way he would be better informed and have more control about his options.”

All participants reported that they found materials in Spanish easier to understand. Three participants wanted more print materials written in “easy” Spanish.

THE CAREGIVERS

- » All look for and get information online.
- » Most get some information from family and friends.
- » Most get some information from a caseworker.
- » Most get information from an advocacy organization (such as ILC or the Area Agency on Aging).
- » Some get information from the ombudsman’s office.
- » Some have friends within HCPF who give them information.
- » Two would trust information gathered at churches.

What do focus group participants think of the printed materials they've received in the past?

"Are they in English?" *Client*

"Sometimes you're reading one thing, I've noticed, and then it tells you to refer to the other, and then it still doesn't even explain the first. It's like a scattered sandwich everywhere and you're trying to put it all together." *Client*

"I like this [ACC handbook]. I've never had anything like this." *Client*

"Every six months they make you fill out all this paperwork—about 38 pages as I recall." *Client*

How would they like to receive program information?

"Normally people don't even know about [the Department's] website, and when they do find out, it's really hard to navigate—because you don't know under which subject you will find the information you want." *Provider*

"My mother, who is 93, would prefer to have something come in the mail. But I would prefer to have something come electronically." *Advocate*

"I would prefer regular mail. I get tons and tons of email, and a message could get lost easily." *Advocate*

"I prefer both, because I think that the piece of paper can be important. The one time you throw something away is the time you have to produce it to prove that you exist. [Paper] is tangible proof." *Client*

"Some letters are written in "formal or legal" language and I don't understand them very well." *Client*

MODERATOR'S NOTES:

- » All caregivers would like to be able to rely on a website for information. Those few who mentioned the Department's website did not like using it. One said, "It's overwhelming."
- » Some participants said they use their phones for texting or email and would want to receive information by email (and one by text).
- » A few participants look for social media sites that provide information.
- » All who used computers wanted a "good" website that is easy to navigate and is updated regularly (confirmed by the date on the page).

What are the most important things they'd want to know before being part of the Demonstration Project?

"Can I keep my same doctors?" *Client*

"Will it cost more? Will it change what benefits I have or don't have?" *Client*

"Some of my prescriptions cost \$600 each, and if I didn't have Medicaid I wouldn't be able to afford them. I worry that if I change something then it's all going to heck and I'll have to restart the process." *Client*

"I would want to know pros and cons—is it going to benefit me or is it not going to benefit me?" *Client*

"What's in it for me?" *Client*

"Who is involved in making decisions about specialists?" *Client*

"Do I have more or less choices than I would have had otherwise?" *Client*

"Why is care coordination good?" *Client*

What do participants think the potential benefits of the Demonstration Project are?

“There will be a coordinated Medicare/Medicaid program in which the differences between the two programs are irrelevant to you.” *Provider*

“This has the potential to use money more wisely, to provide better services and to eliminate waste so that everybody would do better. We have a wonderful acute care system, we have a very broken chronic care system, and that system needs to become person directed.” *Provider*

“Person-centered care coordination means that people will get what they need when they need it, how they want and when they choose it. That’s my ideal.” *Client*

“It will take some relief and stress off you, because there will be somebody to help manage all of your doctors, make sure you get to your appointments, that you’re not doing duplicate tests that aren’t necessary. The RCCOs will be a benefit to the confusion.” *Client*

“The goal is that this system will improve communication between all of the members of the health care team to avoid duplication and to improve your overall health, and that ideally you’ll be the one at the head of the team.” *Provider*

Appendix: Comments from participants

These are unedited comments that participants made during the three focus groups related to their Medicare/Medicaid experiences..

“How do I get more hours? The doctor says two hours is approved. I don’t know who to fight. That’s no fair, because we need more time for care.” *Client*

“I have a coordination of care problem with my main physical provider: I would go to Weight Watchers but it was getting too expensive, so I asked my provider for help in finding some sort of weight loss support group. They suggested something that was too far away. Finally, I went to TOPS but I still hadn’t lost all that weight I’d gained while waiting for the other support group. I could have used someone quicker and better.” *Client*

“I have Medicaid and just got on Medicare. I didn’t even understand about Medicare except that they take \$100 and some dollars off my check. Medicaid doesn’t do that. Colorado Health, I think, said I got eligible for the program.” *Client*

“I don’t understand the paperwork. I read it and tell them to send it to me in Spanish, if that makes a difference. It makes no difference at all. It’s very complicated—the terms that they use. I get the sense of some things, but it’s very complicated, and like she said—they only understand that \$100 and some dollars come out of their money for Medicare. We need some kind of training or more understandable paperwork like when somebody comes in to my office, then I could just explain.” *Staff member from the host facility Client*

“I feel like they sort of purposefully make it difficult; like you said they deny people looking for coverage—we’ve heard that from our families too. They don’t make the information easy to access and they don’t staff phone lines where you can ask questions. But then it costs money, and the more people who receive these benefits, the higher the overall cost. I feel like it’s always money, but that’s part of why it is so hard to access and why there’s no progress on that.” *Provider*

“I have no idea what’s going on. I have Medicare; I don’t have Medicaid. I had a friend who helped me, but she died last year, so I don’t have anyone now. I got hit by a car on Lincoln. I can’t take care of my home but I don’t know how to get someone to come and help me.” *Client*

“I’m confused too about how they handle the age situation. I’m just turning 55 but they said you gotta be 65. I have CO Access, and Chuckie comes out and talks to me, but he’s confused too as to why I can’t get LEAP and all these other programs. . . but then he says you’re not old enough or this disability thing. . .”
Client

“The money that they used to take away from Medicare-now they’re going to give it back to me.” *Client*

“My wife and I are on disability and Medicare. We got a lot of crazy letters from Social Service saying we don’t qualify for this or that, all sorts of stuff, and Colorado Legal Services is the only one who’s been able to help us keep on the Pickle Amendment. . . Without them we’d be up a creek. Medicaid is essential for medications.” *Client*

“My wife and I lost our Medicaid when we got married. So there’s called a Pickle amendment. James Dean wrote the law for the CO Pickle Amendment, and the amendment helped us get it back. He’s with CO legal services. Medicaid pays the \$100 that it would cost us for our Medicare. Medicare Part D is the medication part, and because we have Medicaid we have Medicare Part D. Sometimes a certain medication is not covered under that, but it’s never been a problem.”
Client

“I have both Medicare and Medicaid. My concern is communication between Social Security trying to find things out, like I’m trying to go back to work without losing everything. And I’ve been given misinformation, like I was told I could do a PASS plan, so I put that together. Then Social Security told me I can’t do a PASS plan because you’re SSDI not SSI. If you’re trying to do something to better yourself, there’s no help from these organizations to tell you which direction to go, and that’s really frustrating.” *Client*

"I am a non attorney advocate. We don't use the word "patient," we use "consumer" or "client." We are focused on consumer direction. We are trying really hard to get away from the old medical model, and create a more consumer directed vision so that our disabilities, our age, our health problems do not define us in society."

"All systems are created in the old medical model, and are created to treat us differently." *Client and advocate*

"My mom's 85 and lives in assisted living that specializes in memory care. She broke her hip last year and that's when I noticed her money was running out and I got her on Medicaid. There's that whole gray area that I don't understand, about home and community based services. But it all works. She's in assisted living; a step away from full on nursing care." *Client/provider*

"I'm 81. I receive both Medicare and Medicaid, and I guess I'm a self care giver. There's a lot that I do not know about what kind of benefits are available to me through both Medicare and Medicaid, which is why I'm here-- to learn a little bit more. And I also care for a 97 year old WWII vet. I'm trying to figure out what benefits he should get. . . it's a lot of paperwork for me that I don't quite understand. It's "gov speak," and to try to translate that to something that's understandable to this particular gentlemen who is 97 is very difficult." *Client/Caregiver*

"Last year—about a year ago—I put [my wife] in a nursing home because I could no longer handle her by myself. But as far as Medicare and Medicaid, my opinion is they need to get down to about eight to tenth grade where the average person can understand what's being said." *Caregiver*

“My mom—I had to sign her up for Medicaid. She just passed away, and even the ending of it was not fun, trying to figure out what was paid and not paid. Trying to maneuver on the website to figure it out! Now I’m on the other side. My brother has been diagnosed with FTD and can no longer work. I’m right now in the throes of trying to get him disability. He’s 61. I tell you I’m “legalesed” up to here. There are days I feel like if I’m standing on a cliff and if a strong wind comes along, I’m going to fall off. And I think I’m pretty sharp.” *Caregiver*

“My mother is 91 (soon to be 92) and I’ve been taking care of her since 1995, so it’s been a long time. Of course I’ve taken care of all of the paperwork. I work in this business—I am a social worker—and still it was a total nightmare. And I did take advantage of someone to help me.” *Caregiver*

“It feels like a set up, because anything piece that you might miss—if you submit an application and miss a piece—then you’re at square one again, and you lose a lot of time that way and that time is scary when there’s no money. I don’t have the money to pay her bills. So you have this time pressure of the money going down and the needs going up and systems that aren’t user friendly. And I think I know what I’m doing. What about somebody who’s never done this before! This is terrible.” *Caregiver*

“My father, he’s medical, Medicare. He’s with my mom and she’s not very computer literate. It’s tough for her, by her not being able to keep up with the paperwork. I want to know how I can help. But I don’t even know where to start.” *Caregiver*

“We have created a system that is so complicated that even the people who are experts cannot navigate it.” *Advocate*

“I got here because I said Yes to something; I volunteered for something about “healthcare” and “demonstration.” And that sounds interesting. I think there just needs to be a difference in healthcare; I don’t want someone breathing over my shoulder; I want to say who the RCCOs can talk to (among my doctors), because one may not like me and give me a negative on my diagnosis.” *Client*

“A lot of my experience is as an advocate for my clients; helping them figure out what Medicare pays for what Medicaid pays for, how to access those services. Just filling out the 26 page application is a nightmare for a lot of them, especially caregivers who are working full time and don’t have time to gather all the documents and get everything in order, so that’s where my experience comes from. . . We need a more simplified system and I was hoping that this demonstration would really help with that.” *Provider*

“I’m a senior and I have a disability. I came here. . and became the Executive Director of an independent living center. I learned a lot about independent living, and about Medicare and Medicaid. I remembered that SSI was Medicaid and SSDI was Medicare. Since then I’ve developed a disability as well. I enjoyed the field so much I decided to join it!

“I understand first hand why one needs an advocate. I am very much of an advocate for the person being their own best buddy; understanding and being at the head of their caregiving team. One of the things that I’ve seen that’s going on with the RCCOs is that there seems to be no change; the RCCOs are at the helm and we all are at their discretion, and that bothers me a lot.” *Client*

“I’ve been on Medicare and Medicaid for a few years; I’m in a nursing home on disability. I have seen bad experiences and I have seen other people being hurt. Sometimes you’re just not getting what you need.” *Client*

“I was a full time musician when I came down with MS. When I was 28 I was on SSDI because I was refused Social Security. I feel it’s denied the first time to see if you’re going to come back. That’s wrong, right there. . . the lady next door said, “you should be on Medicare.” So after a few years I did go back after it, and I got on it. It took years; from the time I was 28 to the time I was around 40—to get any kind of help.. .” *Client*

“There’s nothing out there that says “Hey, let’s help you.” I propose we have community announcements on TV that say “If you have become disabled, or you have MS or are beginning to have trouble this is what’s available to you. Because in rural America they’re not going to know... I didn’t know what a disability was about until it happened to me. We need public announcements on radio too. I don’t think it’s been done at all.” *Client*

“I work for [client] five or six days a week. Working for her has opened my eyes to the whole disability thing. I’m not disabled and really there is no one in my family who is disabled, but my Grandma is in a nursing home. You see a lot more when you’re in that life.” *Caregiver*

“I’m the oldest of my generation now caring for my mother. She can no longer deal with independent living (she’s 93) and we are now going through the process within the family of finding a place for her to go. With respect to Medicare, I have the benefit of having worked with the program for many years, but I’ll tell you that you can work for 34 years and still not understand a lot of the aspects of Medicare. It is extremely complicated. It has been amended so many times that’s it’s volumes of coverage rules and that kind of thing. So I have the same kind of issues that many people do. My go to place is online; I go right to the Medicare and You Handbook first, because it’s written in a fairly simple way and it’s easy to understand and it provides links to more in depth.” *Caregiver/advocate*

“When you’re first diagnosed your doctor should know, but they don’t tell you. You have to figure it out for yourself. There should be information on TV and radio. Now I have a voice activated computer, but how many people can afford those?” *Client*

“I’m really very fortunate. I would go to an independent living center, and if I didn’t get my answers there I’d go to CCDC. I have never gone to either Julie or one of her staff when I haven’t gotten a decent answer. They know exactly where to send people. And also the Medicare Handbook; I have found what I’m looking for both times. Sometimes it’s a question of knowing which questions to ask, because if you’re going to look on Google, you’d better know what question to ask.” *Subcommittee member*

“When I started to get on disability it took many many papers that I had to sign and fill out it took over a year to get on disability. And then I got Medicare and then I had to wait two years before they would put me on Medicaid. A minister helped me, he kind of knew some of the ropes. At first he told me that I didn’t qualify, but I said “I don’t have any job. I had to quit my job.” *Client*

“We applied for Medicare and they denied him. We have four or five denials. I say, when you get them can you understand them?” *Caregiver with client*

“We sent four different applications for home care services. Then we got a denial.” *Client*

“Oh my god. I know the system (I have three kids on Medicaid). I just got a letter recently saying “If you like things the way they are, don’t do a thing.” Two weeks later we get a letter that one kids’ been adopted into Denver health. And I even followed the instructions! It’s just really scary. . . but I like the ones with the scorecards and information.” *Client/advocate*

“Do you get the Medicaid letters, like the yellow one that gives you a heart attack Every month your life is on the line. And MAXIMUS just took that over, and I don’t know if that had anything to do with it but they changed it. Every month I was getting three almost identical letters, once saying my daughter had aged out of the system. It’s kind of nice that they combined it, but they did something wrong and that’s how my kid got thrown over into Denver Health” *Client*

“When I was on Medicaid, I needed help everyday, I can’t get out of bed. Every six months they make you fill out all this paperwork—about 38 pages as I recall. You fill it out and they lose it. And then you get “you’re not eligible.” OK my arms and legs don’t work, who’s going to help me fill out all of this again? How many people are dying in their homes because this stuff’s not getting in? So now I walk it in every time and get a receipt. And the reason they lose it that they’re totally understaffed. And they’re talking about cutting costs on that? They can’t do that.” *Client*

“If you’re trying to help a family member who’s in another state—and there’s an awful lot of those especially among Alzheimer’s families –like Jill’s brother-- because of the challenges with Medicare and Medicaid, there aren’t enough physicians who want to take more Medicare patients. People may think “I want to bring my family member to be near me,” not realizing they might not find a doctor.” *Caregiver*

“It would be awesome if each state would have a website that you could click on the state you’re looking for so you don’t have to go to Illinois to look at their site; you could just pick your state and then the information would come up. That would be a lot easier.” *Caregiver*

“It’s extremely difficult to coordinate with all of the [client’s] children; I have to try and coordinate everything through Alaska, where they have extremely different rules and regulations. It’s frustrating to try and please the family by trying to work through Alaska.” *Caregiver*

TELEPHONE VOICE RESPONSE SYSTEMS AND OTHER POTENTIAL SOURCES OF INFORMATION

- » Many in the group are frustrated by interactive voice response systems
- » All complained that they can’t always find information when they want or need it
- » Few Spanish participants use smart phones, email or social media to find information. But there were only five participants, and the moderator does not feel that this is representative of the population as a whole.