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Experienced Voices: What Do Dual Eligibles Want From Their Care?

Insights from Focus Groups with Older Adults Enrolled in Both Medicare and Medicaid

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Research Report

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AARP's Public Policy Institute informs and stimulates public debate on the issues we face as we age. Through research, analysis and dialogue with the nation's leading experts, PPI promotes development of sound, creative policies to address our common need for economic security, health care, and quality of life.

The views expressed herein are for information, debate, and discussion, and do not necessarily represent official policies of AARP.

ACKNOWLEDGMENTS

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EXECUTIVE SUMMARY

In 2007, approximately 9 million older adults and younger people with disabilities were simultaneously covered by both Medicare and some level of Medicaid—a population commonly known as *dual eligibles* or *duals*. Dual eligibles are the poorest, sickest, and costliest of all Medicaid beneficiaries—representing 15 percent of Medicaid enrollees and 39 percent of the program's spending in 2007—with the majority of the costs going to pay for long-term services and supports not covered by Medicare. Duals are also costly to Medicare, accounting for 16 percent of the program's enrollees and more than one-quarter (27 percent) of program spending in 2006.

Because of their vulnerable health status and their costs to both programs, there is considerable interest in exploring ways to deliver high-quality, coordinated services to this population, in an effort both to improve their care and rein in costs. With the federal government administering Medicare and each state administering its own Medicaid program, the delivery of health care services for duals can be fragmented and confusing. Several programs seek to address this fragmentation by offering various types and levels of care coordination for dual eligibles. In addition, the federal government is funding demonstration projects aimed at identifying new, high-quality strategies for delivering care to the dual eligible population.

Missing from the discourse are the voices of dual eligibles themselves. Changes to the way their care is organized and delivered could have profound effects on their health, quality of life, and satisfaction. To address this void, the AARP Public Policy Institute (PPI) sponsored this focus group study of dual eligibles to learn more about their experiences of care across several care models. Between February and August 2011, ten focus groups were conducted in five cities with duals and, in some cases, their family members. We examined duals who were receiving care through the following models: fee-for-service Medicare and Medicaid; enhanced Primary Care Case Management (PCCM); partially integrated Medicare Special Needs plans (SNP); fully integrated Medicare Special Needs Plans; and the Program of All-Inclusive Care for the Elderly (PACE). All participants within each focus group were from the same delivery model.

The following summarizes the general themes that emerged from the experiences of dual eligibles across all of the care delivery models included in this study:

- **Dual eligibles in this study were generally satisfied with their care.**

Duals who participated in our focus group study were generally satisfied with the models through which they were receiving their care. Those who were receiving care coordination through the enhanced PCCM model, both of the SNP models, and PACE were very satisfied with the assistance they received from their care coordinators. High levels of satisfaction were found among those enrolled in the enhanced PCCM model if they were receiving care management services. Those who were not were less satisfied. However, some in the PCCM model had unmet needs for care, highlighting the need to better understand the criteria used to determine "need" for case management services, and whether program participants have an opportunity to request care management services and understand how to do so. Duals enrolled in PACE also appreciated the social aspects of the program, describing the PACE Center as a "home away from home." One area in which duals across all programs (with the exception of PACE) were

experiencing problems was prescription drugs. Despite a federal requirement that beneficiaries be notified about formulary changes, many were taken by surprise over such changes at the point of service. Others were experiencing problems when required to accept generic substitutions.

▪ **Duals moved away from the fee-for-service environment for a variety of reasons.**

A variety of factors influenced decisions to join a partially or fully integrated program. These included the promise of no cost sharing; access to services not currently covered by Medicare or Medicaid, such as dental and vision services; help with medications; and access to transportation services. Most of the duals in this study said they were also influenced by the fact that they did not have to give up their usual providers in order to join these programs, because their providers were participating in the programs they joined. Most people in the New York City (NYC) fee-for-service groups said they were not willing to move away from the fee-for-service model for any reason. People in the enhanced PCCM model did not have to choose between keeping their provider and receiving care management services.

▪ **Although duals in this study strongly preferred having the freedom to select their providers, most were willing to make trade-offs.**

Duals across all of the program models in this study placed a high value on the freedom to select their own providers. Most were willing to give up a usual provider for the following reasons: to avoid cost-sharing obligations, to gain access to care coordination and care planning, to get help accessing needed services and equipment, to gain access to services that are not currently covered by Medicare or Medicaid, to get help organizing medications, and to get help dealing with medical bills. People in this study who were in the enhanced PCCM program, fully or partially integrated SNP programs, and PACE were especially happy that they had the best of both worlds— having their usual providers included in their respective networks so they did not have to make the choice. Only one person in PACE had to give up a provider, but chose to do so to gain access to a program that better met her needs.

▪ **Duals in most of the models of care were receiving bills from their providers.**

Across all of the models of care (except the fully integrated SNPs), many of the duals in these focus groups said they were receiving bills from their providers. However, they dealt with them differently depending on the care model. At least one person in the fee-for-service group said she consulted with another provider about what to do about the bill. Others said they just throw the bills away. Some in the partially integrated SNP knew that they were not responsible for the bills and would write their Medicaid number on them and return them to the provider; or they would give them to their care managers to deal with. A few reported struggling to pay their bills out of their Social Security checks. Those in PACE were the least frustrated because they simply gave their bills to their care managers to deal with.

▪ **Duals in some of the care models reported having problems accessing services.**

With the exception of those enrolled in partially integrated SNPs and PACE, some of the duals in the other models of care experienced problems accessing services. They reported having trouble accessing dental services, accessing specialists, finding doctors who accepted Medicare and Medicaid, getting doctor appointments, and accessing certain

prescription drugs. Several in the NYC fee-for-service and the enhanced PCCM groups mentioned that it was becoming more difficult to find doctors who accept Medicare and/or Medicaid.

- **Most of the dual eligibles in this study saw value in care coordination.**

Most study participants saw value in care coordination. They liked the idea of having someone who they felt would look out for their best interest, take care of things like billing issues for them, and make them feel cared about. Things that made them feel cared about were receiving frequent phone calls from care managers, receiving phone calls alerting them about special health program available to them, and having people check to make sure they have the things they need to manage their conditions (e.g., equipment to check blood sugar). The family members in this study were very pleased that providers were involving them in their loved ones' care planning and keeping them updated. Most in the NYC fee-for-service group—who seemed healthier than those enrolled in the other care models—either did not like the idea of having a care coordinator or did not feel that they were at a point where they needed this type of service. Only one person in the NYC fee-for-service group said that he could use the help of a care coordinator. This individual had a serious chronic illness that requires multiple medications and is associated with a host of other health problems.

- **Most duals in this study lacked experience with the Medicare and Medicaid appeals processes.**

With the exception of the NYC fee-for-service group and one person in the Baltimore partially integrated SNP, most duals in this study had only used the grievance and appeal processes associated with the plans in which they were enrolled and were satisfied that their concerns were adequately addressed through those processes. Some in the PACE groups expressed interest in having a less formal process to express their concerns, because they did not want to be viewed as complainers. Suggestion boxes could be useful in this regard. Among those in the NYC fee-for-service group and the partially integrated SNP, a few had used the Medicaid and the Medicare appeals processes and did not report having difficulty with either process.

- **It gave most of the duals in this study a measure of comfort knowing that their providers communicate with each other.**

Most of the dual eligibles in this study valued knowing that their providers communicated about their care. High levels of provider communication made people feel cared about. Those who knew that their providers were using health information technology to monitor their care and communicate with one another really liked the idea because they felt that it relieved them from having to be the go-between and gave them the feeling that things were not going to fall between the cracks. Some in the NYC fee-for service group—who were relatively healthy—did not care whether their doctors communicated with each other. They felt that they could handle being the go-between with their health information. Some in the NYC groups said that they take pride in being able to manage their own health care, although one person in the NYC group cited an example where good communication among his doctors contributed to his positive surgical outcome.

▪ **Duals in this study had other concerns about their care experiences.**

Other issues raised by duals in this study included problems understanding the Medicare Explanation of Benefits summary, lack of adequate dental coverage, long wait times for transportation services, not understanding of the differences between Medicare and Medicaid, the inability to understand beneficiary materials provided by Medicare, having to juggle multiple insurance cards, and the lack of social activities.

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INTRODUCTION

In 2007, approximately 9 million older Americans and younger people with disabilities were simultaneously covered by both Medicare and some level of Medicaid— a population commonly known as *dual eligibles* or *duals*.[1] Dual eligibles are among the poorest, sickest, and costliest of all Medicaid beneficiaries—representing 15 percent of Medicaid enrollees and 39 percent of the program's spending in 2007—with the majority of costs going to pay for long-term services and supports not covered by Medicare.[2] Duals are also costly to Medicare, accounting for 16 percent of the program's enrollees and more than one-quarter (27 percent) of program spending.[3]

Because of their vulnerable health status and their costs to both programs, there is considerable interest in exploring ways to deliver high-quality, coordinated services to this population, while at the same time reining in costs. To advance this agenda, the recent health reform law created a special office within the federal government—the Federal Coordinated Health Care Office—with the single goal of ensuring that duals have full access to seamless, cost-effective, high-quality health care.[4,5] The same law created the Center for Medicare & Medicaid Innovation (Innovation Center), which is charged with finding ways to improve care and reduce costs by partnering with states and others to identify, test, and spread new care and payment models.[6]

Recently, the Federal Coordinated Health Care Office, in partnership with the Innovation Center, selected 15 states—California, Colorado, Connecticut, Massachusetts, Michigan, Minnesota, New York, North Carolina, Oklahoma, Oregon, South Carolina, Tennessee, Vermont, Washington, and Wisconsin—to receive up to $1 million each to develop proposals for innovative care models. The models that states develop must include interventions that improve quality, care coordination, and cost-effectiveness.[7]

Missing from the discourse are the voices of dual eligibles themselves. Changes to the way their care is organized and delivered could have profound effects on their health, quality of life, and their satisfaction. The AARP Public Policy Institute (PPI) sponsored this focus group study of dual eligibles to learn about their experiences with different models of care, what they want from their care delivery models, and where they experience problems with the way they receive their care.

This project is intended to complement state and federal efforts to develop innovative approaches to serving dual eligibles by offering consumer perspectives on what duals want from their models of care.[8] It is hoped that the federal government and states will benefit from hearing consumer voices as they seek to improve and/or redesign programs to better serve dual eligibles.

Methodology

In December 2010, the AARP Public Policy Institute partnered with Lake Research Partners to conduct focus groups in six cities—New York, New York; Asheville, North Carolina; Charlotte, North Carolina; Baltimore, Maryland; Eau Claire, Wisconsin; and San Diego, California—in order to better understand the experience of dual eligibles in various care models (table 1):

- Fee-for-Service Medicare and Medicaid
- Enhanced Primary Care Case Management Programs
- Partially integrated Medicare Special Needs Plans
- Fully integrated Medicare Special Needs Plans
- The Program of All-Inclusive Care for the Elderly[9]

Table 1
Overview of Characteristics of Care Delivery Models Studied

Program Name	Care Delivery Model	Combines Medicare and Medicaid Funding	Payment Mechanism	Extra Benefits
Fee-For-Service, New York City	Fee-for-Service	No	Any participating provider is paid for each individual service delivered	Adult dental services as a Medicaid state plan option
Community Care of North Carolina	Fee-for-Service plus Enhanced Primary Care Case Management	No	$5 per-member-per-month (PMPM) to primary care provider; $13.72 PMPM to the care network	High-risk individuals receive care management services and referrals to other long-term services and supports as needed
Amerivantage Specialty + Rx Plan	Partially Integrated Medicare Special Needs Plan	No	Plan receives a capitation for Medicare services; beneficiaries are in Medicaid fee-for-service for Medicaid benefits	No cost sharing; vision and dental care; care management services; transportation
Community Health Partnership	Fully integrated Medicare Special Needs Plan	Yes	Capitated payment from Centers for Medicare & Medicaid Services for the Medicare benefit; capitated payment from Wisconsin Medicaid for some LTSS and other benefits.	No cost sharing; transportation, equipment (e.g., shower chairs, scooters, canes)
St. Paul PACE	Fully integrated Medicare and Medicaid program providing medical and social services	Yes	Capitated payment from Centers for Medicare & Medicaid Services for the Medicare benefit; capitated payment from California Medicaid for LTSS and other benefits.	Any service deemed necessary by an interdisciplinary team of providers, including unlimited long-term care services

The project was guided by an Advisory Group (appendix A) that helped develop the discussion guide (appendix B) and identify programs most likely to be providing services to dual eligibles with the characteristics we were looking for. Focus group sites were selected based on ease of finding individuals who were likely to meet our recruitment qualifications:

- Age 65 or older.

- Enrolled in both Medicare and Medicaid.

- Receiving care through one of the specified delivery models.

- No cognitive impairments.

- Able to travel to an interview site.

Because we were seeking to learn about their experiences interacting with the health care system, including experiences with care transitions, two additional screening criteria were added:

- Participants were currently managing multiple chronic conditions.

- Roughly one-half of participants had a recent interaction with a hospital (inpatient or emergency room encounter).

Recruitment efforts were confounded by the fact that many individuals were not fully aware of what programs they were enrolled in, or through which delivery model they were receiving care. In some cases, screening difficulties resulted in a few younger individuals with disabilities being included in some of the groups.[10]

A total of 77 dual eligibles (and in some cases, their family members) participated in the 10 studies—two groups for each of the five models of care (table 2). Focus groups were conducted between February and August 2011. Questions we sought to address were:

- Were these dual eligibles satisfied with their care?

- Why did duals who participated in this study move away from fee-for-service?

- Were these duals concerned about freedom of provider choice? What trade-offs were they willing to make?

- Were these duals having difficulty getting access to appropriate care?

- How did the duals who took part in these focus groups feel about care coordination and patient-centered care planning?

- Were duals in this study experiencing problems navigating the Medicare and Medicaid appeals processes?

- How important was it to these duals that their providers communicate with one another?

▪ **What other issues or concerns did the duals in this study have about the care they receive?**

All of the study participants lived in the community. Some lived on their own in apartments, some lived with family members, and some lived in assisted living facilities or other types of community-based housing. Efforts were made to ensure racial, ethnic, and gender diversity among the groups. With the exception of Eau Claire, Wisconsin, white and African American dual eligibles or family members were represented at all of the focus group sites. Asians and Hispanics were also represented in some groups. Every focus group had both male and female participants (appendix C).

Table 2
Overview of Focus Groups

MODEL	LOCATION	DATE	FOCUS GROUP
Fee-for-Service	New York, NY	August 4, 2011	Two groups with dual eligibles
Enhanced Primary Care Case Management	Asheville, NC Charlotte, NC	May 3, 2011 June 23, 2011	One group with dual eligibles and family members One group with dual eligibles
Partially Integrated Special Needs Plan (SNP)	Baltimore, MD	August 10, 2011	Two groups with dual eligibles
Fully Integrated SNP	Eau Claire, WI	March 9, 2011	One group with dual eligibles One group with family members
PACE	San Diego, CA	February 22, 2011	Two groups with dual eligibles

Group participants were told that the sessions were being videotaped for review purposes and for the purpose of developing a final report, but that the sessions were confidential and that they would not be identified in the final report. The New York and Baltimore groups were observed by AARP staff through a one-way mirror in one location and a video feed in another. All focus group participants were given $100 for their participation in the study.[11] In addition, we provided transportation for many participants to eliminate a barrier to participation.

Study Limitations

Efforts were made to include participants with diverse health needs and experiences. However, the voices of the frailest dual eligibles with more serious illnesses, including cognitive impairments, are underrepresented in this study. Understandably, it can be very difficult for people who are seriously ill to attend focus group studies. Fortunately, at a couple of the focus group sites, we were able to learn about some of their experiences through the perspectives of their family members.[12] It should be emphasized that this study seeks to learn from the beneficiary perspective and does not include objective measures of quality of care.

The main purpose of focus group research is to draw upon respondents' attitudes, feelings, beliefs, experiences, and reactions in ways that would not be feasible using other

methods.[13] However, these types of interviews are inherently susceptible to the influence of groupthink (i.e., people expressing an opinion that is in line with the rest of the group even if that opinion is at odds with their personal opinion or belief). It is also possible that one or two individuals will dominate the group, creating an inaccurate view of the group's overall opinions and beliefs. We believe that the skills of the primary investigator minimized this result.

Providers associated with some of the focus group sites helped identify and select focus group participants, creating the opportunity for bias in the selection process. Finally, the findings in this report may not represent the experiences of all dual eligibles or even all dual eligibles who resemble participants in this study. However, they make an important contribution to a broader discussion about duals, their experiences, and their preferences for how they receive their care. Going forward, it will be important to conduct more research to test specific hypotheses developed from the themes that emerged from this study in order to inform the broader discussion in ways that can be generalized to the broader dual eligible population.

Organization of the Report

This report is organized by each of the care delivery models included in the study. We begin with the least integrated delivery model (fee-for-service) and end with the most structured delivery model (PACE). For each model, we provide a brief description of the model in general and the specific program from which study participants were recruited, and a summary of major findings. We conclude the report with a summary of major themes derived from all of the groups, and a list of strategies designed to address problems that emerged from the focus groups.

DETAILED SUMMARY OF FINDINGS

Fee-for-Service Medicare and Medicaid: New York, New York

Fee-for-Service Medicaid in New York City

Most older dual eligibles are not enrolled in managed delivery systems for either their Medicare or Medicaid benefits. Rather, they typically receive their Medicare—and, if eligible for full benefits, their Medicaid services through what is called a fee-for-service (FFS) delivery system. In a FFS system, dually eligible beneficiaries have unrestricted choice among Medicare and Medicaid participating providers, their providers are reimbursed for each individual service delivered (without incentives to limit utilization), and beneficiaries (or a family member or friend) are largely responsible for managing and coordinating their care. In 2010, duals living in New York City (NYC) accounted for about 54 percent (or 400,000) of the state's dual population. Of this number, about 309,000 of the duals in NYC were over 65, accounting for $6.9 billion in the state's Medicaid spending in 2010—70 percent of which was spent providing long-term services and supports to the population. In NYC, most dual eligibles receive their care in a fee-for-service environment, with only 15 percent—or 45,000—enrolled in managed care in 2010.[14] The Medicaid program in NYC does not provide extensive case management or care coordination services to the dual population. However, the city has several large medical centers— Mount Sinai, Beth Israel, Columbia Presbyterian, and others—with associated physician group practices and sophisticated health information technology systems. Many of the fee-for-service duals at the NYC site were receiving their care through these centers and may have been receiving some level of care coordination that was not transparent to them.

Major Findings

- **Many in the groups were receiving their care through hospital-based systems with associated physician practices. These individuals reported being very satisfied with their care.**

Many of the people in both groups were receiving their health care through physician group practices associated with large hospital systems with sophisticated health information systems and were very pleased with their care. These individuals may have been receiving some level of care coordination that was not transparent to them. One woman said, "All I know is that I am not giving up my Mt. Sinai for anybody…I will pay if I have to."

- **Most cited good communication among their doctors; others didn't care.**

"They [all of my doctors] were all sitting around my bed, and that was a wonderful thing to see. The hospital told my primary care [doctor], and then my primary care told the others."

Many said that their various doctors communicated well with one another. One woman referenced a time when her doctors conferred at her bedside during a recent hospitalization: "I was put into the hospital because my pressure went up, my lung doctor came in, and another one came in, my ear doctor came in. They were all sitting around my bed, and that was a wonderful thing to see. The hospital told my primary care [doctor],

and then my primary care [doctor] told the others." One man didn't care whether his doctors communicated or not: "Like I say, as long as I'm satisfied with my doctors, I don't care whether they communicated or not."

▪ **Those who valued good communication among their providers appreciated the role of health information technology in facilitating communication among their various providers.**

Referencing the electronic health record, one man stated, "They've got everything on the computer. My GP [general practitioner] looks up my internist on my record. It's all on the computer, and I can get in there too."

▪ **Participants reported having had good care transition experiences.**

Several people cited having had good experiences with post-hospital care coordinated by a hospital social worker. Social workers helped some arrange for visiting nurses and other care after they left the hospital. Speaking about her post-hospitalization experience, one woman said, "They follow up when you leave, it was unbelievable."

▪ **Many reported experiencing difficulty getting the prescription medication they needed.**

Many participants cited problems accessing prescription drugs. They reported having difficulty getting some of their prescriptions because the medications were not covered by their plans. Others were struggling with high out-of-pocket costs for

> *"I'm supposed to take two [pills] a day, but I take one [to save money]."*

certain medications. One man said he is not taking as much pain medicine as he needs because he is trying to save money. He said, "He [the doctor] gave me 30 mg of Oxycodone which I take once [a day]. I'm supposed to take two a day, but I take one." One woman's brand-name drug was no longer covered, requiring her to move to a generic that was not effective. She said, "All of sudden they cut me off. They wanted me to take the generic. My doctor said no, it's no good, and they [the prescription drug insurer] said she has to do this for six months. So, I did it for a month, and my blood pressure shot up and my doctor called and screamed and yelled at them. I made a letter, and I got it back." Complaining about formulary changes, another woman said, "Here's my dilemma. Right now, as we speak, I'm paying for it [prescription drug]. And it's like $225 I'm paying out of pocket and I'll tell you why. It's not on their list. My doctor called up three times to tell them that that's what I needed and so far, it's been a month and they haven't done anything about it. I'm due to switch companies, I think in December…. I'm gonna' call Medicare and tell them that I'm not satisfied with the prescription drug company." Another woman said, "I have the same problem. I got denied. And my doctor, he's the chief of special surgery, he called himself the prescription company and he couldn't get it for me. "So I'm doing without it. They wanted $275 for 30 and I said no."

- **Many were concerned that a lot of doctors were no longer accepting Medicaid and Medicare.**

Several participants were worried because doctors were refusing to take Medicare and Medicaid patients. One man, for example, said, "Well, a lot of doctors are quitting altogether, Medicare too, let alone Medicaid. You have to ask who accepts Medicare." When asked if they worry about doctors leaving Medicare, one woman responded, "Most good doctors are opting out of

> *"Well, a lot of doctors are quitting altogether Medicare too, let alone Medicaid. I mean, you have to ask who accepts Medicare."*

Medicare. They don't want to take anything. They are not taking insurance because they're not getting paid. Every other month I get a letter saying, 'We're not accepting any insurance anymore.' It's been happening for the last five years, but now it's very bad."

- **Some expressed a lack of confidence in the quality of their providers.**

> *"I find the doctors that take Medicare are halfway decent. The doctors that take Medicaid are not."*

While most liked their doctors—especially their primary care physicians—a few described experiences in which they did not feel cared for or were otherwise unsatisfied with the care they received. One woman had little confidence in doctors who take Medicaid: "I find the doctors that take Medicare are halfway decent. The doctors that take Medicaid are not."

- **People were generally not interested in having a care coordinator.**

The people in the NYC fee-for-service group were relatively healthy and were not using long-term services and supports. This may explain their lack of interest in care coordination. One woman said, "Thank God I don't need it yet." Another woman said, "I don't think I'm ready for it either." A man in the group offered, "I think the worst thing is to have one [a social worker]. All I'd hear is complaints." Another woman said, "I have a living will. That's my social worker, that's my everything. If I'm out, if I'm not lookin' good, just cut the line. Let's get it over with."

- **Many did not understand the purpose of the Medicare Explanation of Benefits statement.**

Many of the duals in these groups didn't understand their Medicare Explanation of Benefits statement. One woman expressed her frustration, saying, "The only problem, it was not the doctors, it is the billing system. They will send you a bill, how it is broken down, what Medicaid is paying, what Medicare is paying and what you should be paying, what you don't pay. I don't understand why they have to tell you all of this."

> *"They will send you a bill, how it is broken down, what Medicaid is paying, what Medicare is paying and what you should be paying—I don't understand…."*

▪ **They were frustrated because they were getting bills from providers and also wanted help understanding what Medicaid and Medicare cover.**

> *"There should be someone, maybe a caseworker, who is assigned to you who makes things very clear. It's too complicated."*

A woman reported getting a bill that she didn't understand, saying, "I've had my primary [doctor] for seven years and I just got a bill from her for $460. She claims that she has to charge now for giving blood tests. She says that it's not covered under Medicare or Medicaid. I already checked into another doctor and I'm not gonna' pay." Some participants didn't understand the differences between their Medicaid and Medicare coverage. One man expressed his frustration as follows: "I am not sure when my Medicaid begins and my Medicare ends. I know my Medicaid is paying for certain prescriptions and my Medicare is paying for others. I would like it to be explained because I feel like an idiot not knowing and it was never explained to me. There should be someone, maybe a caseworker, who is assigned to you who makes things very clear. It's too complicated."

▪ **Most were reluctant to give up their current providers.**

> *"If you don't have the money, there goes your choice."*

Most of the participants in these groups were receiving care through large hospital-based systems with associated primary care providers and extensive health information technology support. People who received their care through these systems had the perception that they were receiving good care coordination and were therefore reluctant to move away from their providers. A man in the group said, "I am not leaving Mount Sinai." A woman said, "I don't intend to change [doctors]. If I have to pay, I have to pay, because I am not going anywhere else." Another woman summed up a feeling among the group, saying, "If you don't have the money, there goes your choice."

▪ **People in fee-for-service Medicaid appreciated the program's dental benefit.**

Most were pleased that Medicaid offers dental coverage. However, some experienced difficulty getting certain dental procedures covered. One woman whose dentist accepts Medicaid said, "Well, my dentist takes Medicaid, and I needed a root canal, and Medicaid doesn't do that. I don't know how he [the dentist] did it, but he got it done. They had another reason that they wouldn't cover, and I got it for nothing. I've been going to him for 11 years."

▪ **People were familiar with the Medicaid appeals process, and a few had used it successfully.**

Several were familiar with the Medicaid appeals process. One woman said, "If they turn you down, you can always appeal." Another woman was currently using the appeals process. A third woman had used the appeals process successfully despite being told by her social worker that "any time you go for an appeal, you're going to lose." No one in the group reported having used the Medicare appeals process.

▪ **Many in the group had strong negative feelings about managed care, but no real experience with the model. At least one person said he could accept managed care if he could keep his usual provider.**

> *"I don't want these HMOs telling you where to go or who to see. I want whatever dignity I have left under these care systems."*

Most in the group valued personal choice and had negative reactions to any suggestion that they might benefit from a managed delivery system. One man said, "I don't want these HMOs [health maintenance organizations] telling you where to go or who to see. I want whatever dignity I have left under these care systems. I want to be able to use it myself. That's it. [If I had to be in an HMO] I would fight it. I wouldn't do it." However, he said that he could be fine with managed care "as long as I keep my same doctors." A woman said, "Managed care is not very managed. It's mismanaged." Another woman offered the following perspective: "I have a doctor I can debate an issue with, ask a question, he doesn't get upset about it. I can tell him I found something on the Internet. I mean, stuff like that…and it's a very personable thing and that's what I like. Managed care isn't like that." Another woman said, "I don't want to go to the doctors they recommend. I want to go to people that I'm comfortable with." Another woman said, "I like to be able to take care of myself. I pride myself on that. I don't need anybody to help manage my health."

▪ **People liked the idea of a single card for Medicare and Medicaid.**

Participants said that it can be confusing to deal with multiple cards and supported the idea of a single card that gives them access to all of their services (Medicare and Medicaid). One participant put it this way: "I wouldn't mind having just one card. Sometimes it's embarrassing to bring out your Medicaid card." Another said, "I have more than two cards. For my prescriptions, I have two others, and God knows who they belong to."

> *"I wouldn't mind having just one card. Sometimes it's embarrassing to bring out your Medicaid card."*

Primary Care Case Management: Asheville and Charlotte, North Carolina

Community Care of North Carolina

Primary care case management (PCCM) programs are managed fee-for-service programs used by some state Medicaid agencies as an alternative to comprehensive risk-based managed care.[15,16] Under a PCCM model, enrollees have a designated primary care provider (PCP) who is paid on a fee-for-service basis for health services rendered. In addition, the PCP receives a small monthly *add-on* payment for each enrolled Medicaid beneficiary to coordinate the services the beneficiary receives and to influence the appropriate use of specialists and hospital services.[17] A variation on the basic PCCM model could involve an *enhanced* case management fee, with a portion of the fee going to the primary care provider and the remainder going to an administrative entity to organize wraparound services for beneficiaries.[18]

One example of the enhanced PCCM model is Community Care of North Carolina (CCNC). CCNC is a public-private partnership between the state and community care networks.[19] Each network receives an enhanced care management fee—$13.72 per member per month (PMPM)—from the state Medicaid agency to provide care management services to dual eligibles. These payments are used to hire local community health teams, including case managers, or otherwise pay for the resources necessary to manage enrollees. Fourteen networks around the state are responsible for managing the care of enrollees and are required to link beneficiaries to PCPs, who serve as medical homes. Medicaid provides an additional payment of $5.00 PMPM to support the activities of the medical home. The emphasis of the program is on care management and continuous quality improvement.[20]

The program began enrolling older people and people who have disabilities in 2008. Initially, the dually eligible population had the option to voluntarily enroll. In 2010, the program received permission from the Centers for Medicare & Medicaid Services (CMS) to mandate enrollment in the enhanced medical home model with an opt-out provision. Individuals are enrolled by either the department of social services or the state Medicaid agency. Enrollees receive a letter that informs them that they have been enrolled in the program and that they have the opportunity opt out of it.

Because the program targets only at-risk individuals, not every person who is enrolled in CCNC receives care management services. Health information systems help the program to identify high-cost users and other at-risk individuals. As a general rule, the factors used to identify "at risk" individuals include things like: high-cost users, number of chronic conditions, utilization of in-patient hospital care, and emergency room utilization.[21] Since mandatory enrollment began, duals are being phased into the program in an attempt to keep patients linked to their existing PCPs. Currently, approximately 150,000 dual eligibles are enrolled in CCNC. For purposes of this project, we conducted focus groups with CCNC program participants in Asheville and Charlotte, North Carolina.

Major Findings

▪ **Most people in the Asheville groups were aware that they were a part of CCNC, while several participants in Charlotte were not.**

Because the program delivers care management and other wraparound services only to high-risk individuals, it is possible for people to be enrolled in the program and not realize it because they are not currently receiving care coordination or wraparound services. One man who is blind and lives alone in the community said, "I need help. I have to ride the bus to get groceries. I don't have any help." He was not aware that he was enrolled in CCNC.

▪ **People wanted to do as much as they could for themselves.**

A few people in the groups said they refused care management and other services even when they were offered. One woman said, "I'm very independent. I don't want a care plan. I can do for myself." Another said that she had been offered help at home but refused it because she didn't feel she needed it at the time.

▪ **People who were receiving care coordination reported high levels of satisfaction. They relied on care coordinators to help them navigate the health care system.**

> *"I'm very appreciative that I do get it, especially when you hear about cuts. [Without a care coordinator], I wouldn't know all of the resources available."*

Those who knew they had a care coordinator were satisfied with a number of things. One woman said, "I'm very appreciative that I do get it, especially when you hear about cuts." Another woman explained how much she loves having someone call her and check in on her. She said, "Yes, I love [weekly check-ins by my caseworker] them. I live by myself and I'm a scared person." Most said they were pleased with the how their care was coordinated when they were hospitalized and when they transitioned back to their homes. Another woman said, "I have [name withheld] for my care manager. He goes out of his way to do things for me." She also said that her care coordinator essentially saved her life by recognizing her mental health needs and helping arrange appropriate care.

Participants said that Care coordinators helped them—

➢ Obtain durable medical equipment
➢ Arrange for personal care assistance and visiting nurses
➢ Arrange for help with grocery shopping and meal preparation
➢ Access services such as rehabilitation and mental health services
➢ Receive in-home checkups on a regular or semiregular basis

When asked what things would be like without their (or their loved one's) care coordinator, participants said—

➢ "Nothing would get done."
➢ "I would become so frustrated."
➢ "I would be on the phone for hours trying to figure things out."
➢ "I wouldn't know all of the resources available—they know about services I would never know about."

▪ **Many were worried about lack of access to doctors and dentists.**

Many in the PCCM groups reported problems finding a doctor who accepts both Medicaid and Medicare. And, like dual eligibles at other focus group sites, these participants said it was especially difficult to find dentists who accept Medicaid. One woman said, "Dental care in this area is very bad. You can't get one." Another woman said, "There's only one dentist in Asheville who will make you dentures." One man explained that he does

> *"That's the only reason I hadn't changed doctors yet, because I hadn't found a doctor that would accept both [Medicare and Medicaid]. As soon as I can find a primary doctor for me that will accept both of them, trust me…."*

not like his current doctor, but has not changed because of access issues. He said, "That's the only reason I hadn't changed doctors yet, because I hadn't found a doctor that would accept both [Medicare and Medicaid]. As soon as I can find a primary doctor for me that will accept both of them, trust me.…" Others in the groups said they experienced difficulty accessing specialists.

- **People reported having smooth transitions from the hospital.**

Everyone in the PCCM groups who had experienced a recent hospital stay said that they had help with the transition back to their homes and that their care coordinator helped get the services they needed. However, many felt that things fell through the cracks in the area of prescription drugs. Many reported being taken off their usual medications during a hospitalization, only to have their PCP put them back on the same medication. This resulted in some confusion about whether or not they should resume their prior regimen. One woman said, "When you go to the hospital, the doctors rearrange your medications. But when you get discharged, your primary care doctor puts you back on them." They said they didn't understand why their hospital medication regimens differed from what they were taking as outpatients.

- **Some reported experiencing balance billing problems.**

"They were collecting what Medicare would not pay them.…I've never had that happen to me before."

Some in the group were frustrated by *surprise* bills they received when something was not covered. One woman explained a recent experience, saying, "I went [to the urologist] yesterday and I liked the doctor very much. There was a lot that he had to do. When it came time to check out, they said I owed them $30. They were collecting what Medicare wouldn't pay them. I've never had that happen to me before. I'll get a bill, but if it's not covered by Medicare, it's covered by Medicaid. They don't accept Medicaid and I found that out at that time."

- **Participants were not sure whether their various providers communicate with one another.**

One woman reported that her medical primary care provider and her heart doctor don't talk to each other: "I usually have to help out and give information." Another woman said, "I don't know if my doctors are talking to each other or not.

- **People enrolled in CCNC would be reluctant to change doctors in order to be in the program.**

No one in the groups said they had to change doctors to be enrolled in CCNC. Almost all said they would have been unwilling to give up their usual doctor to be in the program. Fortunately, program managers understand this and are making efforts to ensure the broadest possible provider network.

- **Some were confused about the differences between Medicare and Medicaid.**

Some of the group members understood the differences between the two programs. As one woman explained it, "What one won't pay, the other will." Others were confused about what each program covers.

▪ **People have experienced problems with the transportation services.**

One woman recalled a time when the transportation service forgot to pick her up, resulting in her missing a doctor appointment. A family member in one of the groups told us that his mother uses the van service to get to appointments, but he was frustrated because the van picks his mother up at 10 a.m. for an 11 a.m. appointment and doesn't bring her home until 5 p.m.

▪ **People did not report any difficulty using the Medicaid appeals process.**

People in both groups were not having problems with appeals. One man said, "Your doctor can help you work the system to get you what you need." One woman had used the Medicaid appeals process and did not find it particularly difficult. Another woman said that

> *"Your doctor can help you work the system to get you what you need."*

when she has a problem, she calls the hotline number on the back of the Medicaid card. She finds this helpful. Another woman said she had been denied Medicaid, but used the appeals process successfully and was given Medicaid eligibility.

▪ **People in these groups did not report difficulties having two cards—one for Medicare and one for Medicaid.**

Most people in these two groups said they did not experience problems having two cards. As one man put it, "They usually just ask for my Social Security number." Another said, "They keep a copy of your cards so you don't always have to pull them out." People did, however, wish that their cards were laminated. One man said, "How do they expect this piece of paper to last?" Another man said, "It [the Medicare card] doesn't last a year."

▪ **They were eager to have more opportunities to socialize and would like to see this as a feature of their health care delivery system.**

Some group members responded enthusiastically to the idea of having a place to go to receive services and to socialize at the same time. They felt that it would help them overcome loneliness. A woman noted that "Having somewhere to go and something to do helps with depression." A man said he liked the idea of having more opportunities for social interaction "because you get very lonesome being by yourself."

Partially Integrated Medicare Special Needs Plan: Baltimore, Maryland

Amerivantage Specialty + RX Plan

The Medicare Prescription Drug Improvement and Modernization Act (MMA) of 2003[22] created a new type of Medicare Advantage (MA) plan[23]—the Special Needs Plan or SNP—to encourage health plans to develop targeted programs to integrate and coordinate care for high-risk beneficiaries, including dual eligibles, more effectively.[24] Although not defined in federal law, for purposes of this study, we define partially integrated dual SNPs as capitated health plans through which dual eligibles receive their Medicare-covered services, while receiving their Medicaid services in a fee-for-service environment.

In 2007, Amerigroup established *Amerivantage Specialty + RX Plan*—a Medicare Advantage SNP to for Medicare-eligible beneficiaries in central Maryland.[25] In addition to standard Medicare benefits, this partially integrated SNP provides its dually eligible enrollees with limited transportation services and vision and dental care. The health plan offers SNP enrollees access to a 24-hour nurse advice line, assessments and care planning services, health education classes, and coverage up to $100 per quarter for over-the-counter medications. Members also receive an annual allowance to obtain various assistive devices through a mail order catalog program. These devices are helpful to members with disabilities or impairments of mobility, dexterity, hearing, or vision.[26] As of October 2011, the company had enrolled about 1,445 dually eligible beneficiaries in central Maryland, including Baltimore, Anne Arundel, Montgomery, and Prince George's counties.[27]

Major Findings

▪ **People heard about program in a variety of ways.**

Some participants heard about the program from family members and friends. One person said she received a brochure in the mail. Some participants said they learned about the program from a representative of the health plan. One man learned about it from a plan representative who was in the doctor's office or clinic. He explained, "I was coming from one of my appointments … and one of their representatives was there and they explained it to me."

▪ **The promise of no cost sharing and additional benefits was very attractive to participants.**

> *"…[an Amerigroup representative] told me, 'No co-pays.' I signed up."*

Some said that they decided to go with Amerigroup because they would no longer have to deal with cost sharing. Recalling a conversation with an Amerigroup representative, one woman said, "I was with [another insurance company] and there were a lot of co-payments with [that insurance company] but with Amerigroup they said, 'Forget the co-payments, we pay the whole thing.'" Many also said they enrolled because of the vision care, dental care, or the transportation benefits. One woman recalled, "Amerigroup was explaining to me what they had to offer. For glasses, they would pay for the exam. They would pay for the glasses. They paid for some of my medicine. If I am not mistaken, I think they offered transportation. If I didn't have transportation, they would figure out a way for me to get back and forth to the doctors and stuff." Although people were largely satisfied with the extra services, they felt that the dental benefit should be expanded to include dentures. One woman said, "They [the dentists] take care of your cleanings, fillings, and pullings, but they don't make plates." Other reasons for enrolling in Amerigroup were the plan's affiliation with a large "top-rated" medical center, access to a helpline, help filling out forms, having "a person you can call," and having people "check on you to make sure you have what you need." Another person said, "It's personalized."

▪ **Most reported being satisfied with their care.**

When asked to rate their satisfaction with their health care, most participants gave ratings of seven or higher (on a 10-point scale). One person gave her care a five. Although generally satisfied, some participants also gave examples of things that went wrong or things they did not like about their care. For example, some complained about receiving bills from providers and not getting the medications they need to manage their pain. Only one person complained about the lack of good communication from his care manager.

▪ **People liked the reminders and check-ins they received from Amerigroup staff.**

> *"They sent me a letter two days ago saying I need to get a glaucoma test on my eyes."*

Participants expressed appreciation for the phone calls, visits, and mailings that they receive from Amerigroup staff. Staff check in with members to see how they are doing, to make sure their test results (blood pressure and blood sugar) are normal, and to remind them to make appointments for medical exams and other medical needs. One woman said, "I am a diabetic. They [Amerigroup] sent me a letter saying that I need to get my eyes checked because of my diabetes. I found that helpful." Another woman said, "They call to tell you about special programs they have going on." A man said, "They [care coordinators] call you all the time."

▪ **Members felt that Amerigroup staff truly care about them.**

Participants felt that staff genuinely cares about them. They formed these impressions because of the check-in phone calls and from their perceptions of friendly and caring attitudes among the staff. One woman mentioned how important it is for someone to check in on "people like her," saying, "…because at our age we need that." A man explained how someone checks in on him and how this makes him feel cared for: "They call me and see if I have my machine to take my blood pressure [and check] my diabetes. They will ask me how I feel, 'Are you doing alright?' They are really friendly. They really care."

▪ **People liked having a care manager and wanted a care plan that is updated as their needs change.**

People in these groups liked having someone who takes care of their problems, looks over their care, and checks on them. People were especially pleased that in some cases, the care manager would make home visits to check on them and arrange for transportation to medical appointments. One

> *"I would recommend this program to anyone because they really look out for you."*

woman said, "My care manager checks on me to make sure everything is OK. She wants to know how I'm doing. I can call her and leave a message and she'll call me right back." One person said, "I would recommend my social worker. I call her to keep her up on my health." When asked whether she liked the idea of a care plan that is continually updated, one woman said, "Sure, I think it's a good idea. We need that because things change." Another woman said, "That would be great. Your needs change, you need updating."

▪ **People had mixed experiences with care transitions.**

Some did not experience problems with care transitions and felt that they received the appropriate care after being discharged from the hospital to their homes. One woman who had a nurse and a therapist visit her at home after back surgery said, "They're the reason I am walking today. Amerigroup and the hospital arranged everything." Another woman said, "When I had my knees done, I had some therapy at the house for about seven days and that went well. When I left the hospital, they [Amerigroup] made all of the arrangements." Others experienced problems with their transitions. One man complained that his care fell through the cracks after his hospitalization for back surgery. He said, "Somebody came by to see me in the hospital and offered for me to go to a rehab center or a nursing home, but it didn't happen. …Yeah, something fell through the cracks."

▪ **Some were frustrated because they were receiving medical bills.**

Many in the partially integrated SNP groups were attracted to the program because they were told that they would not have any out-of-pocket costs. Nonetheless, some were still receiving bills from providers. One frustrated woman who was deferring other needs to pay the bills said, "What gets me is when they [providers] send them [bills] to you, which you are not supposed to be getting them, it goes on your credit. It [the bill] might

> *"I got a bill from my mammogram and that one was pretty big. I thought it was going to get done for free. …They told me I could pay $15 a month."*

not be that big, but it's still a bill that takes away from my [Social Security] check." Another woman said, "I got a bill from my mammogram and that one was pretty big, and I'm still paying it. I thought I was going to get that done for free, but I'm paying like over $100. They told me I could pay $15 a month." Another person in the group experienced problems with collection and credit issues. This man said, "I had a bill [but] I didn't receive the bill. I got a call from the collection agency for the overdue bill."

> *"There should be a way that me as a consumer or client could call another number to see if they were BS-ing me."*

One woman explained, "When you go to the hospital or say, for instance, the eye clinic, they should know [if] they are going to send you an extra bill because they know what kind of work they are going to do most of the time. They should be able to know somewhat if I have to pay something more than what Medicare or Amerigroup won't be able to pay instead of me getting the bill in the mail." Another woman said, "They tell you that you don't have a co-pay, but later on, you look in the mail and here comes a co-pay bill." One man expressed frustration about this issue and said he wishes there were a way for him to know what's covered and what's not covered on his own. He said, "I had a similar situation and also maybe a solution. There should be a way that me as a consumer or client could call another number to see if they were BS-ing me."

▪ **There was some confusion about the differences between Medicare and Medicaid.**

When asked about the differences between the two programs, one Baltimore dual eligible summarized, "Well, all I know is that if Medicare doesn't cover it, the other program certainly won't."

▪ **Some complained of miscommunication with their care managers.**

While some participants know their care managers by name and seem to have regular interaction with them, others do not. Some mentioned instances of miscommunication with their care managers and doctors. One man said that he had to change doctors because his care manager did not communicate well with him: "My doctor is all right. They discharged me because the lack of communication. I missed an appointment. It wasn't my fault."

▪ **Most people felt that their providers were communicating with one another.**

People generally felt that their providers communicate with each other. One woman said, "They all work together at the clinic I go to." Another woman said, "I go to the clinic and we have a head doctor, and if anything goes wrong, she tells us to call her and she'll come down and see what's going on. And we have the dentist and when we go to the diabetes group, we have the pharmacy come in

> *"You don't even have to tell the doctor what is wrong with you or what you are on. They already have it on the record. I think it's good."*

and talk to us and the doctor is right there too." Another woman said she likes that her providers use electronic health records because "…you don't have to tell the doctor what is wrong with you or what you are on. They already have it on the record." One man, who receives his care from a community clinic, said, "I go to a small community clinic, but everyone communicates well together. They all work together at the clinic I go to." Another man said, "I only go to two doctors—my pain manager and my primary care doctor. I tell them what's going on." Another man reported poor communication among his providers. He said, "As far as communication, I have to be aggressive and I have to bring everybody up to speed."

▪ **Participants expressed support for the use of electronic health records (EHRs).**

Many in the group realized that their doctors are using EHRs to communicate about their care. One woman said she likes EHRs because "…you don't even have to tell the doctor what is wrong with you or what you are on. They already have it on the record. I think it's good." Another woman said, "They are doing it [using HIT] more now. They didn't used to use it, but they're doing it now. Every doctor I go to uses the computer, and they find out everything they want to know about me. I think it's a good thing. You don't have to tell the doctor what's wrong with you. They already have it in your record." A man said, "I've actually seen my doctor sit there in front of me and pull up my information to see if I had my lab work done. …I like that."

- **People preferred to keep their own doctors, but were willing to make trade-offs to gain other types of benefits.**

> *"[Amerigroup] got me a good doctor."*

Most in the groups said that it was very important for them to keep their same doctors, "because they already know your medical history." Only a few had to change doctors when they enrolled in Amerigroup, but this did not seem to have bothered them too much. One Baltimore woman was pleased with her new doctor, saying, "They got me a good doctor." Another woman explained that she did not have to switch doctors, but it would not have been a problem. She said that keeping her doctor was not that important to her and she was sure that her new doctor "would have been just as good as long as they treated me well and treated my illness and stuff." Another woman said she didn't really mind changing doctors, "As long as they get me a doctor and they treat my ailments." Most people were very happy that Amerigroup had contracts with their existing providers. Although the stated preference was to keep their own doctors, when asked whether they would be willing to change doctors in order to get access to more care management and a care team, the response was unanimously yes.

- **Some were frustrated by the limitations on transportation services.**

Some people in the partially integrated SNPs were frustrated by limits on their transportation services. These individuals reported having many doctor appointments and would often use up their allotted transportation services, resulting in their having to find alternative ways to get to their appointments. One woman said, "If you need it, they should give it to you."

- **People were interested in having a single card for Medicare and Medicaid.**

Like those in the fee-for-service group, people in the partially integrated SNP groups said it would be much easier to have a single card rather than to juggle multiple cards. One woman said, "They should make it…put all of our [insurance] information on one card, and it shouldn't be a paper card because it rips and then you've got to call and get a new one. Well, everything else has gone plastic, why not." A man said, "There should be a universal card."

- **Only one person reported using the Medicare appeals process.**

Only one man from the groups had used the Medicare appeals process. He did not seem to be having difficulty with the process. He said, "I got a notice from a collection agency, actually, I never saw a bill. It was over two CAT scans. I called Amerigroup and they tried to help me. I ended up going to an appeal with CMS. I'm still in the middle of it."

- **Some would like to have social needs addressed in their care.**

> *"When you sit down and elaborate with each other on behalf of your condition or on behalf of your Medicaid, it gives a person a sense of knowledge."*

Some of the people in these groups expressed interest in having their social needs addressed and in attending day centers. One woman felt that socialization activities helped older people deal with depression. A man said

it would be helpful to meet with others who have the same health conditions he has: "When you sit down and elaborate with each other on behalf of your condition or on behalf of your Medicaid, it gives a person a sense of knowledge." A woman said, "We need more social gatherings because there is so much going on in our neighborhoods that we cannot control. … So we can get together and talk about our problems."

Fully Integrated Medicare Special Needs Plan: Eau Claire, Wisconsin

Community Health Partnership

In fully integrated SNPs, the targeted group—in this case, dually eligible Medicare beneficiaries—receive their Medicare *and* Medicaid services through a capitated arrangement with a MA health plan.[28] The health plan contracts with Medicare to provide the Medicare benefit package and enters into a separate contract with the state Medicaid agency to provide some level of Medicaid benefits. Fully integrated SNPs that target dual eligibles—dual SNPs—provide an opportunity to better coordinate and integrate their care by offering a full array of Medicare and Medicaid benefits.[29]

Community Health Partnership, Inc. (CHP) is a fully integrated Medicare SNP that has a contract with the Centers for Medicare & Medicaid Services (CMS) to provide the Medicare benefit package—hospital services, primary care (including some behavioral health services), and pharmacy—to dual eligibles. The program also contracts with the Wisconsin Department of Health Services (the state Medicaid agency) to provide Medicaid benefits—home and community-based waiver services and other long-term services and supports (LTSS)—to the same population. The program is voluntary. However, to be eligible for CHP, individuals must have a nursing home-certifiable level of care. As of October 2011, 1,658 dual eligibles were enrolled in CHP.[30]

CHP members receive care management and service delivery that is coordinated by an interdisciplinary team consisting of the member, a registered nurse, a nurse practitioner, a social service coordinator, and a team assistant, along with the member's primary physician. CHP provides services to eligible individuals in five Wisconsin counties: Chippewa, Dunn, Eau Claire, Pierce, and St. Croix. As of October 2011, 1,658 dual eligibles were enrolled in CHP.[31] The program is optional for Medicare and for Medicaid beneficiaries.[32]

Major Findings

▪ **People learned about CHP in a variety of ways.**

Some heard about CHP through a social worker or staff members in a hospital or rehabilitation facility. Several people indicated that they were looking for something new to help with costs and learned about this option through the Council on Aging. Others learned about CHP through friends.

▪ **People joined CHP for a variety of reasons.**

Participants or their family members gave many reasons for joining CHP. These included no cost sharing, saving money on medication, the fact that CHP includes family members in care decisions, improved access to things they needed (e.g., scooters, shower chairs, canes), and help with medications. As one man put it, "They told me that they would help me take care of my medicine, help me take care of my physical therapy, and a few other odds and ends which were hanging out in the wind.

> *"They told me that they would help me take care of my medicine, help me take care of my physical therapy and a few other odds and ends which were hanging out in the wind."*

When they told me they were going to take care of that, I said okay, that's fine." One woman said, "They help you right away." Another woman said, "The CHP people actually care."

▪ **Participants and their family members were satisfied with the care they received through CHP.**

> *"They've met every expectation I've ever had."*

Overall, participants and family members indicated high levels of satisfaction with CHP. One of the things participants really appreciated was that "if you need something, CHP will help you get it." For example, one participant said, "It's top-notch. I couldn't ask for any better. Like everybody has said, you ask for something or don't ask for something, they are there with it. They've met every expectation I've ever had." Another woman described how she could not stand very well on her own and requested a shower chair. Now she uses it all the time. She said that without CHP she might not have purchased the chair and would have continued to struggle.

One family member explained how she thinks her mother's health has improved because of her assisted living facility and the care she gets through CHP. She went on to explain how this has helped them as a family as well: "I think it's been a really good thing for us kids, because now we have the quality time to spend with her [mom], rather than spending two hours and doing her cooking, her cleaning, her laundry, her meds. They take care of her meds, her three meals a day, and it's just fantastic." There was a sense among participants that CHP staff genuinely cares—and this seemed to mean a lot to them. As one woman put it, "I find … that the CHP people that do come in the house, they actually care. They really do."

▪ **Participants valued the inclusion of family in their health decisions.**

Participants and family members appreciated the efforts CHP staff makes to involve families in care decision making. One woman said, "They go ahead and get this for me but they have the kids come and look at the stuff." Another woman said, "They include your whole family. I can't say enough about that."

> *"They include your whole family. I can't say enough about that."*

▪ **They expressed appreciation for the team approach to care used by CHP.**

"It makes me happy because of them we are spending a lot more time with our kids than we were doing before."

Participants discussed their "teams"—consisting of a doctor, nurse, social worker, and others—and how they help coordinate their care and track their progress against identified goals. One man talked about how his [father's] team looks after him in a holistic way, helping him pursue nonmedical goals like spending more time with family, going to church, and fishing. Another participant followed up by saying, "They want you to have as much of a real life as you can have. It makes me happy because of them we are spending a lot more time with our kids than we were doing before."

▪ **The groups felt that their providers were communicating with each other.**

People generally felt that there were high levels of communication among members of their or their loved one's care teams (consisting of their primary care provider, nurses, nurse practitioners, a social worker, and the transportation person). Most agreed that even though their specialists were not a part of the basic team, their primary care providers communicated with them. However, one person reported "falling through the cracks" when his primary care doctor and his diabetes doctor miscommunicated about his Coumadin (blood-thinning medication), resulting in a hospitalization.

▪ **These dual eligibles appreciated the in-home assistance they received.**

Participants and their family members expressed appreciation for the in-home assistance they received to help with meals, cleaning, laundry, and bathing. One family member said, "They saved me a lot of grey hairs.… We have somebody that comes in the morning to give [my mother] her pills, and then there's another lady that comes after that...they're wonderful…I mean, if she needs help with the shower or whatever."

▪ **They liked having their medications taken care of by CHP.**

"CHP is taking care of these medicine trays that I get every week from the pharmacy… I am so happy with it."

Many also mentioned how much they appreciated how CHP handles all of their medications, making it easier for them. For example, one man said, "Right now, CHP is taking care of these medicine trays that I get every week from the pharmacy. I have nothing to do with setting up my medicine anymore. It comes to me set up. I take it like a good little boy four times a day, and it works out just fine. I am so happy with it."

▪ **They were pleased with the assessment and care planning process.**

"I really appreciate that CHP is building a relationship with the client so that they know them and if something is going on, they are able to assess it…."

Family members were especially pleased with the evaluation process and care plan development process. Talking about CHP's evaluations, one woman explained, "CHP actually was fantastic with my mom. When we

have our evaluations through Our House Assisted Living Facility, CHP coordinates with them. So we do one roundtable discussion, with CHP and Our House Assisted Living at the same time. And they have sheets and sheets of paper, and they go through everything you can imagine, from dressing herself, to her personal needs, or her bathroom needs. And then they rate it, as far as if she needs more help, or less help. And they work really well together. And yes, I'm at all of those." One man said, "Sometimes it seems like overkill [frequent updating of care plans], but I really appreciate that CHP is building a relationship with the client so that they know them and if something is going on, they are able to assess it…they become like family members, and that's what I want…someone watching out for my mother. If I can't be there, I would rather have somebody that I can trust."

▪ **Most people were experiencing successful care transitions.**

Most people reported having had successful transitions from the hospital. Some were transitioned to temporary nursing home stays, some to their homes with support from nurses and other caregivers, and others to their homes with family support. In addition, their team nurses provided frequent checks. These individuals felt that things went well for them. One family member said, "The nurse from CHP was very involved in my mom's care transition…she was awesome." Only one person felt that his care "fell through the cracks" because he was discharged over a weekend.

▪ **Some reported being confused about what Medicare and Medicaid cover.**

> *"It is confusing knowing what they cover at times."*

Family members said that it was difficult to know what is covered by Medicaid versus what is covered by Medicare. One man said, "It's confusing understanding what each program covers. The 'Medicare and You' mailing is confusing. I only read what I need to." Another man said, "It is confusing knowing what they cover at times." They are grateful that the Chippewa County of Department of Aging conducts monthly meetings to educate consumers on Medicare and Medicaid. Family members really appreciated this service and felt that they were able to get their questions answered. They felt that between this service and CHP, all of their questions were answered.

▪ **They were frustrated because they often learned that their prescription drug coverage had changed when they received a bill for services provided.**

One woman was frustrated by the lack of communication when medications that were previously covered were no longer covered. Describing a time when a medication was discontinued from coverage, she said, "I think sometimes we find that, with the prescriptions, all of a sudden…someone will be getting prescriptions for years, and then one month

> *"And it's like you can't find out ahead of time. You have to wait until you get the bill. And then you go, 'Ow.'"*

we'll get a bill, and it will say, 'You owe $1,236.' And we'll be like, 'Oh, something's wrong here.' And then you'll call, and you'll find out that the prescription's no longer covered. And you have to try to find a different prescription that the plan will cover. And it's like, you can't find out ahead of time. You have to wait until you get the bill. And then you go, 'Ow.'"

- **They were confused by the Medicare and You publication.**

Many said that the Medicare and Your publication is confusing and overwhelming. As one man explained, "We got like a Sears catalog that thick saying this is your Medicare for 2011. Well, I don't think there are 3 percent of senior citizens that will read it." He goes on to say, "I tell you this much. This senior citizen only reads what he needs to read as he goes along. I won't sit down and read the whole thing because it is too confusing for me."

- **Several complained about difficulty getting doctor appointments.**

> *"Dental is like really, really hard to get."*

When family members were asked if there were any problems with the care their loved ones were receiving, many mentioned that getting [doctor] appointments is not always easy. One male family member said, "getting an appointment is sometimes difficult." Others agreed, and one woman said, "Dental is like really, really hard to get."

- **Most did not have to give up their providers to join CHP.**

Most of the CHP participants did not have to give up doctors because they were already participating providers for CHP. A few people gave up their dentists, but they felt the trade-off was worth it. There was general agreement that people would have changed doctors if they had to in order to gain access to the care coordination and other services offered by CHP.

- **People were not experiencing problems with the internal CHP appeals process. They had not used the formal Medicare or Medicare appeals processes.**

> *"After an unsuccessfully appealing his mother's denial for a power wheelchair, one man said, "It was probably the right decision for Mom and from the taxpayer perspective."*

Like Amerigroup's partially integrated SNP program, CHP has its own appeals process, which several people had used. One family member used the process to prevent CHP from cutting the number of hours for which her husband could be reimbursed for providing care to her mother. Another used the process to get CHP to pay for transition lenses for her mother. One family member was denied a power chair for his mother, but felt "it was probably the right decision for Mom and from the taxpayer perspective." Another person reported using CHP's appeals process when "they tried to take away some of my physical therapy." She successfully used the process to get her therapy reinstated. No one in these groups had used the formal Medicare or Medicaid appeals processes.

- **People were interested in seeing all of their providers in the same place.**

Interviewers described to the group a model of care in which people receive all of their services (primary and specialty care) at a single site. All group participants were enthusiastic about the idea. One of the reasons is that so many of these people had experienced long waits when using transportation services. For example, their appointment

might end at noon, but they might have to wait until 2 p.m. for the van to pick them up and take them home. People had high levels of dissatisfaction with long wait times.

▪ **People identified limitations in what CHP is able to provide.**

Although most felt that CHP is an excellent program, some shortcomings were identified. One family member said that CHP "is awesome when it comes to providing for home care…but for institutional placements, they are not as thoughtful." A guardian said she likes CHP for the most part, "but it's hard to place people with chronic brain injury

> *"It's hard to place people with chronic brain injury because CHP doesn't pay well for these people."*

because CHP doesn't pay well for these people." Another guardian agreed, saying, "The rates they set [for these complex types of patients] are inadequate."

▪ **People did not report having trouble using multiple program cards.**

Participants, their guardians, and their family members did not report having problems with multiple cards because they used the CHP card as their primary card and because they received lots of support from the CHP staff in negotiating services.

A Program of All-Inclusive Care for the Elderly: San Diego, California

St. Paul PACE Program

The Program of All-Inclusive Care for the Elderly (PACE) is a medical and social service program that combines federal and state funding to keep frail older people living in the community for as long as possible. Authorized by the Balanced Budget Act (BBA) of 1997, PACE is a capitated benefit that delivers a comprehensive service package—including long-term services and supports—using integrated Medicare and Medicaid financing. As of November 2011, there were 82 programs in 29 states serving about 23,000 people.[33,34] PACE programs are required to provide all Medicare- and Medicaid-covered services—including hospital and nursing home care—and any other services determined necessary by the interdisciplinary team.[35] To qualify for PACE, individuals must be—

- ➢ Age 55 or older
- ➢ Living in a PACE service area
- ➢ Able to live safely in the community at the time of enrollment
- ➢ Nursing home eligible (i.e., considered "frail")[36]

The St. Paul PACE program was established in March 2008 by St. Paul's Senior Homes & Services, a San Diego nonprofit organization with a mission to provide "a caring network of medical and social services to promote independence and dignity that enable San Diego's chronically ill elderly to remain at home."[37] The program currently enrolls 170 people and provides services at its PACE center to about 55 older people per day (or just over one-third of those enrolled in the program). Onsite services at the PACE center include a large day center that provides activities and hot meals, a spa and bathing facility, a physical and occupational therapy area, a gymnasium, and a full medical clinic.

Off site, the PACE program provides home care, including light house cleaning, laundry, shopping, meal preparation, bathing, and medication management.

The number of times people are required to come to the PACE center is determined by their physical or psychosocial needs. For example, an individual who would benefit from daily socialization, or who needs daily medical intervention (e.g., diabetes or wound care) or physical therapy might be prescribed a daily visit to the PACE center. Individuals with lesser needs might come to the center only once or twice a week.[38,39]

St. Paul's PACE program employs one full-time physician, six registered nurses, one physician's assistant, two physical therapists, one occupational therapist, ten home care providers, and eight day center workers. Once a month, the center employs the services of specialists.

Major Findings

- **Participants heard about PACE from a variety of sources.**

Participants recalled hearing about PACE in a variety of ways. Many learned about the program from friends who were enrolled in or had otherwise heard about the program. One person learned about PACE through the CMS "Medicare and You" publication. One woman recalled learning about PACE when someone from the program spoke at her building; another found out about PACE when she saw the building while riding the bus.

- **Enrollees turned to PACE for a variety of reasons, including help with organizing their health care needs.**

Reasons for enrolling in PACE included frustrations with the care they were previously receiving, and the benefits that PACE provides. Many participants complained that they were having a difficult time getting the care they needed or wanted in their previous health care arrangements. Some participants also mentioned difficulty paying medical bills and having a sense that their doctors were not listening to them. One participant said, "I was having trouble with medical care, getting services, getting equipment I needed and getting help. I was looking for a program that would help me and take care of me, provide me the treatment."

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"The 'A' in PACE is the key word. All-inclusive care–that's what sold me."

Some of the main reasons participants were drawn to PACE included feeling that they would have better access to doctors, help with medical transportation, and assistance provided for household chores and errands. One participant explained, "I came here because there is better access to doctors, and one of the reasons I joined PACE is because I have a psychologist and a psychiatrist and

they have made a big difference in my life. I get to see the same doctors [at the PACE center] because when you go to the [outside] clinic you always see a different doctor."

The holistic nature of the program and having everything under one roof were very appealing to most participants. As one participant put it, "The A in PACE is the key word. All-inclusive care—that's what sold me."

▪ **Enrollees were very satisfied with their care.**

The participants reported high levels of satisfaction with their care. When asked to rate their satisfaction with their care under PACE on a scale from one (very unsatisfied) to ten (very satisfied), all participants gave ratings of nine or ten. Expressing his appreciation for PACE, one man said, "I don't know of any other insurance company or place that has all of the things that PACE has." A woman followed up his comment by saying, "We love it here." Another said, "Tell Washington we need more of these."

▪ **Having bills and appointments taken care of was a very attractive feature of PACE.**

"I don't even open the envelopes anymore. I just bring it down to PACE."

They appreciated knowing that they did not have to worry about anything when it came to making appointments or handling bills. They found relief knowing that PACE would take care of everything, and they trusted the program to do everything that is needed for them. For example, one man described how he kept getting bills, but he trusted PACE to deal with them: "For some reason, the hospital keeps sending me bills, but I don't know why. I don't even open the envelopes anymore. I just bring it down to PACE."

▪ **They felt valued by PACE staff.**

PACE enrollees felt valued, respected, and listened to at PACE. One woman explained, "When I come for an emergency or something, as soon as I walk in, the staff members, they come and they greet you with a smile; they make me feel welcome."

▪ **They liked the convenience of receiving services under one roof.**

PACE enrollees liked the convenience of having all (or most) of the services they need in one place. They especially appreciated how the program arranged transportation if they needed to see a specialist who was not housed in the building. As one man described it, "If you need a specialist that is not here they will send us transportation to get there. Also, they send somebody from PACE with you [to your medical appointments]."

▪ **They appreciated the in-home assistance that allowed them to stay in their homes.**

In discussing what they liked about PACE, many participants said they liked the fact that PACE allowed them to continue living in their own homes and maintaining some level of independence. The in-home care they received as part of the program was key to being able to continue living in the community. People also mentioned that they liked the

help they got with household chores such as vacuuming and washing dishes, running errands, grocery shopping, and assistance with personal care and bathing.

- **They felt they could count on PACE staff for whatever they needed.**

> *"I know that anything that ever happens to me, PACE will be there for me."*

Participants had a lot of good things to say about their doctors, nurses, and social workers. Everyone had a social worker, and most said that their social workers are responsive to them and even know what medications they are on. They also mentioned their doctors as one of the best parts of the program. Overall, participants indicated a high level of trust and satisfaction with the PACE personnel. It was important to them that almost all of their care providers were located in the same place, and they felt that they could easily get the care they needed and answers to their questions. Many said that when they had an emergency or had to go to the hospital, they called PACE first (or second if they needed an ambulance). PACE staff were their go-to people—the people they felt they could count on. One woman captured this sentiment well when she said, "I know that anything that ever happens to me, PACE will be there for me."

Another woman described her sense of security and trust in PACE staff. "I am not afraid anymore. I am taken care of; people care about what happens to me. Those people that come here, and they are here when I come three days a week, and the staff is wonderful. No matter if I question things, if I feel something should be paid more attention to or I bring something up, I am not judged for that. I am considered all valuable and treated that way with respect. They consider what you are saying and try to explain things."

- **Most did not understand differences between Medicare and Medicaid.**

Although most people said that they did not understand the difference between Medicaid and Medicaid, it didn't matter to them because, as one man said, "With PACE, we don't have to know. They take care of everything."

- **The PACE facility was described as a "home away from home" for some.**

Participants indicated that they felt at home when they are at the PACE facility. In the words of one woman, "I think some of us describe this as a home away from home." Many liked the social aspects of being at the facility, mentioning the chance to be with

> *"I think some of us describe this as a home away from home."*

friends and the ability to chat casually with doctors and nurses in the hallways. One man pointed out, "Another thing is, you are not sitting in a doctor's office reading a magazine that you really don't want to read while you are waiting for the doctor. You can be here doing things that you want to do while you are waiting for your appointment." Another participant added that the music at the facility is good, and many agreed. Participants also mentioned that the PACE staff members give them Christmas gifts and Valentine's Day cards; these personal touches seemed to make a difference to them.

- **They said their health was improving because of the care they received through PACE.**

> *"I have emotional problems, but I get care here for it."*

Most participants said that their health had improved since they joined PACE. Many specifically mentioned how the physical therapy and mental health services have helped them. One man said, "I have emotional problems, but I get care here for it." One woman described her improvement this way: "[My health is] very good since I joined PACE. They have helped me transfer me back and forth to the doctors, and I am very happy and satisfied because they are very concerned about me and my health."

- **They liked having regular assessments of their needs and progress.**

Participants also cited the six-month assessment as an important part of the care they receive with PACE. They liked the checkups because someone from PACE comes to their homes to do a detailed interview, assess what additional services they may need, and note the progress they have made toward identified goals. One woman explained that during one of her assessment visits it was determined that she could use more help getting groceries. She explained, "When they are asking about this for the assessment, I told them that I was without wheels. They provided somebody."

- **They have had positive experiences with care transitions.**

People who had experienced hospitalizations were generally happy with their care transitions. One person who was discharged from the hospital to a rehabilitation center said, "My social worker was on top of everything and kept me in the loop. When I finally went home, I was able to manage." Another man who broke his wrist went from the hospital to a skilled nursing facility for two weeks before going home. He said, "It was a good process."

- **Some worried that PACE may not always have the capacity to serve them well.**

Some participants complained that there are sometimes long waits for services and meals and that the common areas at the PACE center were getting too crowded. They realized that the program is growing and taking on more and more members. A couple of participants referred to this issue as

> *"They keep adding more people, so the building is getting full."*

"growing pains." One man explained, "They keep adding more people, so the building is getting full." Another man said, "You have to have more patience, and at mealtime it takes a little bit longer." Overall, they do not see this as a big problem right now, but they worry that it will be a problem if PACE does not expand its space and staff.

- **People in this PACE program were generally satisfied with communication among their providers, but a few identified areas for improvement.**

Most felt that there was good communication among their providers. One man said, "I've never seen files like my doctor keeps about me. They showed me so many records of my visits and care that it is really unbelievable." Others felt left out of discussions about their care at times. For example, one woman explained, "That bothers me to a certain extent, but I don't know how they can change it. They have team meetings about what equipment someone might need, what referrals they might send and we are not part of those meetings. We are not asked for input about why it is important to us or what we feel we need or what we want. We are told and it happens without us there. I agree that I don't have any idea how they can work that out." Another woman mentioned another issue with communication, saying, "There is so much that goes on and so much happens, sometimes the message doesn't get through and you have to ask a few times… it is not a major disaster but there it is; it doesn't get through from one group to another group."

> *"There is so much that goes on and so much happens, sometimes the message doesn't get through and you have to ask a few times…it is not a disaster, but there it is; it doesn't get through from one group to another group."*

- **One slight disadvantage of PACE is the chance that members might have to give up their doctors.**

While most were satisfied with the care they receive from their PACE doctors, at least one man mentioned that a slight disadvantage of PACE was having to give up a good doctor if he or she is not associated with the program. Specifically, he said, "One of the slight disadvantages to PACE [is] if you have a doctor that you really like you probably won't have him anymore. I had a neurologist that I really liked, but he is not a part of PACE." Another man said that he gave up his psychologist, but he did not mind. A woman also gave up her doctor, but didn't mind because she prefers the "one-stop shopping." Finally, one man took the creative route and convinced the program to make his doctor a participating provider.

> *"One of the slight disadvantages to PACE [is] if you have a doctor that you really like you probably won't have him anymore."*

- **People had not used the formal Medicare and Medicaid appeals processes. However, they were satisfied with the internal grievance process the program uses to resolve disputes.**

People in the groups were aware of the PACE program's grievance process. One man actually used the process and said it worked well for him: "They even apologized." People did not need to use the more formal Medicare and Medicaid appeals processes. However, some participants mentioned that they would like a new system to report problems they are having with the program. Currently, they are asked to fill out a "grievance report" if they would like to point out a problem or if they have a complaint.

Participants said that they do not like the idea of a grievance report because they do not want to be perceived as "complaining" or causing any problems. They simply want a way to point out an issue that could use improving.

▪ **People did not find it confusing to have multiple cards.**

People enrolled in this program rely on their PACE program card to access services. Even though they have cards for Medicare and Medicaid, they seldom are required to use them. One man said, "Sometimes the specialists don't know what the PACE card is, but the older the program gets, the more doctors know about it."

PUTTING IT ALL TOGETHER

Themes

The following are themes that emerged from conversations with dual eligibles across all of the focus group sites. These themes may not be not representative of the perspectives of duals who have similar characteristics to those who participated in this study; as such, we hesitate to generalize to the entire dual eligible population. With this caveat in mind, we offer the following themes:

▪ **Dual eligibles in this study were generally satisfied with their care.**

Duals who participated in our focus group study were generally satisfied with the models through which they were receiving their care. Those who were receiving care coordination through the enhanced PCCM model, both of the SNP models, and PACE were very satisfied with the assistance they received from their care coordinators. However, some in the PCCM model had unmet needs for care, highlighting the need to better understand the criteria used to determine "need" for case management services, and whether program participants have an opportunity to request care management services and understand how to do so. Duals enrolled in PACE also appreciated the social aspects of the program, describing the PACE Center as a "home away from home." High levels of satisfaction were found among those enrolled in the enhanced PCCM model if they were receiving care management services. One area where duals across all programs (with the exception of PACE) were experiencing problems was prescription drugs. Despite a federal requirement that beneficiaries be notified about formulary changes, many were taken by surprise over such changes at the point of service. Others were experiencing problems when required to accept generic substitutions.

▪ **Duals moved away from the fee-for-service environment for a variety of reasons.**

A variety of factors influenced decisions to join a partially or fully integrated program. These included the promise of no cost sharing; access to services not currently covered by Medicare or Medicaid, such as dental and vision services; help with medications; and access to transportation services. Most of the duals in this study said they were also influenced by the fact that they did not have to give up their usual providers in order to join these programs, because their providers were participating in the programs they joined. Those whose doctors did not participate were less satisfied. Most people in the NYC fee-for-service groups said they were not willing to move away from the fee-for-service model for any reason. People in the enhanced PCCM model did not have to choose between keeping their provider and receiving care management services.

▪ **Although duals in this study strongly preferred having the freedom to select their providers, most were willing to make trade-offs.**

Duals across all of the program models in this study placed a high value on the freedom to select their own providers. Most were willing to give up a usual provider for the following reasons: to avoid cost-sharing obligations, to gain access to care coordination and care planning, to get help accessing needed services and equipment, to gain access to services that are not currently covered by Medicare or Medicaid, to get help organizing medications, and to get help dealing with medical bills. People in this study who were in the enhanced PCCM program, fully or partially integrated SNP

programs, and PACE were especially happy that they had the best of both worlds—having their usual providers included in their respective networks so they did not have to make the choice. Only one person in PACE had to give up a provider, but chose to do so to gain access to a program that met her needs.

▪ **Duals in most of the models of care were receiving bills from their providers.**

Across all of the models of care (except the fully integrated SNPs), many of the duals in these focus groups said they were receiving bills from their providers. However, they dealt with them differently depending on the care model. At least one person in the fee-for-service group said she consulted with another provider about what to do about the bill. Others said they just throw the bills away. Some in the partially integrated SNP knew that they were not responsible for the bills and would write their Medicaid number on them and return them to the provider; or they would give them to their care managers to deal with. A few reported struggling to pay their bills out of their Social Security checks. Those in PACE were the least frustrated because they simply gave their bills to their care managers to deal with.

▪ **Duals in some of the care models reported having problems accessing some services.**

With the exception of those enrolled in partially integrated SNPs and PACE, some of the duals in the other models of care were experienced problems accessing some services. They reported having trouble accessing dental services, accessing specialists, finding doctors who accepted Medicare and Medicaid, getting doctor appointments, and accessing certain prescription drugs. Several in the NYC fee-for-service and the enhanced PCCM models mentioned that it was becoming more difficult to find doctors who accept Medicare and/or Medicaid.

▪ **Most of the dual eligibles in this study saw value in care coordination.**

Most study participants valued having a care coordinator. They liked the idea of having someone who they felt would look out for their best interest, take care of things like billing issues for them, and make them feel cared about. Things that made them feel cared about were receiving frequent phone calls from care managers, receiving phone calls alerting them about special health program available to them, and having people check to make sure they have the things they need to manage their conditions (e.g., equipment to check blood sugar). The family members in this study were very pleased that providers were involving them in their loved ones' care planning and keeping them updated. Most in the NYC fee-for-service group—who seemed healthier than those enrolled in the other care models—either did not like the idea of having a care coordinator or did not feel that they were at a point where they needed this type of service. Only one person in the NYC fee-for-service group said that he could use the help of a care coordinator. This individual had a serious chronic illness that requires multiple medications and is associated with a host of other health problems.

▪ **Most duals in this study lacked experience with the Medicare and Medicaid appeals processes.**

With the exception of the NYC fee-for-service group and one person in the Baltimore partially integrated SNP, most duals in this study had only used the grievance and appeal processes associated with the plans in which they were enrolled and were satisfied that

their concerns were adequately addressed through those processes. Some in the PACE groups expressed interest in having a less formal process to express their concerns, because they did not want to be viewed as complainers. Suggestion boxes could be useful in this regard. Among those in the NYC fee-for-service group and the partially integrated SNP, a few had used the Medicaid and the Medicare appeals process and did not report having difficulty with either process.

- **It gave most of the duals in this study a measure of comfort knowing that their providers communicate with each other.**

  Most of the dual eligibles in this study valued knowing that their providers communicated about their care. High levels of provider communication made people feel cared about. Those who knew that their providers were using health information technology to monitor their care and communicate with one another really liked the idea because they felt that it relieved them from having to be the go-between and gave them the feeling that things were not going fall between the cracks. Some in the NYC fee-for service group—who were relatively healthy—did not care whether their doctors communicated with each other. They felt that they could handle being the go-between with their health information—some in the NYC groups said that they take pride in being able to manage their own health care. Although one person in the NYC group cited an example where he appreciated that his doctors communicated with each other and felt this was the reason why his surgical outcome was successful.

- **Duals in this study had several concerns about their care experiences. The most important concern was related to receiving bill from providers.**

  Other issues raised by duals in this study included: problems understanding the Medicare Explanation of Benefits summary, lack of adequate dental coverage, long wait times for transportation services, not understanding of the differences between Medicare and Medicaid, the inability to understand beneficiary materials provided by Medicare, having to juggle multiple insurance cards, and the lack of social activities.

LOOKING AHEAD

Issues for Further Exploration and Research

Although what duals in this study told us may not be representative or generalizable, there is much we can learn by listening to their voices. Based on themes that emerged across the groups, we have identified the following questions that could be the subject of future research. This list is not exhaustive, but represents possibilities for a research agenda.

- How can access to dental providers and specialists be improved for duals, regardless of their service delivery model? Can other health care costs be avoided by improving the dental status of dual eligibles?

- What are the best ways to educate beneficiaries and providers about the federal prohibition on balance billing for duals? What are effective strategies for educating beneficiaries about what to do when they receive these bills?

- What can be done to improve transportation for dual eligibles who rely on this service, no matter what their care delivery model is?

- Does social isolation increase health care costs? Is there evidence to support adding assessments for social isolation to the annual Medicare wellness visit? If so, what are appropriate interventions to address the problem regardless of care delivery model?

- Is it feasible to try to develop a single, laminated "smart" card that combines Medicare Parts A, B, and D for beneficiaries who are in fee-for-service and partially-integrated SNPS?

- What are effective strategies for providing consumers with education about the differences between Medicare and Medicaid? How can the Medicare and You publication be made more useful for consumers?

- What are promising strategies for helping duals obtain objective information about the various care options available to them? How can policymakers and service providers develop programs that help duals (and their families) find the care model that best meets their needs?

- Duals were interested in sharing advice and experiences about their health care with each other. What kinds of programs can be developed to facilitate peer-to-peer discussions among dual eligibles with similar health conditions? Can this be accomplished in a pure fee-for-service environment?

- Are there ways the Medicare Explanation of Benefits summaries can be more consumer friendly? Could making the summary more consumer friendly support CMS's fraud detection efforts?

- What are the best ways to educate beneficiaries about their right to receive notices of Part D formulary changes and what to look for when they receive such notices?

- Would the use of pharmacy transition coordinators be an effective strategy to improve medication management and health outcomes when duals transition from one care setting to another?

CONCLUSION

The voices of the 77 dual eligibles in this study tell us a lot about what they want from their health care, their likes and dislikes, their needs and preferences, their problems, and some of the factors that influence the choices they make about taking care of their health and staying in the community. Most important, we learned that the duals are not a homogeneous group; they vary in health status, care needs, and desire for autonomy vs. dependence. Some duals are more vulnerable than others. Some want to be taken care of; others want to be more engaged in their care. However, because most duals have multiple chronic conditions, it is important that they have a usual source of care, raising questions about the appropriate role of each of these models of care in ensuring that duals have a primary care provider.

As policy makers seek to identify care models that can deliver high-quality, cost-effective care to the duals, it is important to develop a range of options that are compatible with the variation in needs and preferences among consumers. It is also important to identify components of systems or programs that currently work well for duals and incorporate them into new care models.

ENDNOTES

[1] David Rousseau et al., *Dual Eligibles: Medicaid Enrollment and Spending for Medicare Beneficiaries in 2007* (Washington, DC: Kaiser Commission on Medicaid and the Uninsured (KCMU), December 2010), *http://www.kff.org/medicaid/upload/7846-02.pdf*.

[2] Ibid.

[3] Medicare-Medicaid Coordination Office, *People Enrolled in Medicare and Medicaid*.

[4] The Patient Protection and Affordable Care Act, Public Law 111-148, March 23, 2010.

[5] Centers for Medicare & Medicaid Services, *About the Medicare-Medicaid Coordination Office*, http://www.cms.gov/medicare-medicaid-coordination/.

[6] Centers for Medicare & Medicaid Services, *About the Innovation Center*, http://innovations.cms.gov/.

[7] If the federal government approves a state's model, the state will receive additional federal funding to move into the development and implementation phase of the project. L. Flowers and W. Fox-Grage, *Health Reform Law Creates New Opportunities for States to Save Medicaid Dollars*, Insight on the Issues (Washington, DC: AARP, July 2011).

[8] This project focuses on dual eligibles age 65 and older in order to complement another focus group project being funded by CMS that highlights the experiences of younger dual eligibles who are living with disabilities.

[9] Not every possible model of care is represented in this study. We do not include people who are enrolled in mandatory managed care for Medicare or for Medicaid.

[10] We did not include young, disabled duals in this study because CMS was conducting focus groups with that group.

[11] In two locations—New York and Baltimore—participants who arrived at the focus group site at least 15 minutes before the focus group start time had their names entered into a lottery to receive an extra $100. Lake Research Partners has found that offering an early bird lottery improves attendance and ensures that participants will not be late for the groups. The early bird approach was not used in every site in deference to the on-the-ground recruiter's methods.

[12] It should also be noted that this study does not include all of the care models. For example, it does not examine the experience of duals who are mandatory managed long-term care programs.

[13] D. L. Morgan and R. A. Kreuger, "When to use focus groups and why," in *Successful Focus Groups*, ed. D. L. Morgan (London: Sage, 1993).

[14] New York City Medicaid Expenditures and Utilization for CY 2010.

[15] Stephanie E. Anthony et al., *Medicaid Managed Care for Dual Eligibles: State Profiles* (Washington, DC: Kaiser Commission on Medicaid and the Uninsured, October 2000).

[16] State interest in PCCM programs was driven by the following: (a) A desire to increase access to care. First, by offering physicians a small payment, state officials hoped more providers would accept Medicaid beneficiaries. Then each beneficiary would choose or be assigned to a participating physician, rather than needing to locate a provider who would accept Medicaid on his/her own; this physician would serve as the beneficiary's medical home. (b) A desire to save money by reducing inappropriate emergency room and specialist use and other high-cost care. With continuity of care established, the member would presumably contact this medical home, rather than the emergency room, when health problems arose. Moreover, continuity of care would, in all likelihood, lead to better quality of care as well as more preventive care. (c) A belief that PCCM would be more palatable to physicians than risk-based managed care. (d) The belief that PCCM was better suited than MCOs in certain areas, such as rural regions where it would be difficult for MCOs to maintain an adequate population base for financial viability. Joanne Rawlings-Sekunda, D. Curtis, and N. Kaye, Emerging Practices in *Medicaid Primary Care Case Management Programs* (Portland, ME: National Academy for State Health Policy, June 2001).

[17] Under a PCCM model, the primary care provider can be an MD, Federally Qualified Health Center, community health center, rural health center, local public health department, maternal and Child Health clinic, Indian Health Service clinic, tribal clinic, nurse practitioner, physician assistance, or nurse midwife. Rawlings-Sekunda et al., *Emerging Practices in Medicaid Primary Care Case Management Programs*.

[18] Rawlings-Sekunda et al., *Emerging Practices in Medicaid Primary Care Case Management Programs.*

[19] Douglas McCarthy and Kimberly Mueller, *Community Care of North Carolina: Building Community Systems of Care through State and Local Partnerships* (New York, NY: The Commonwealth Fund, June 2009).

[20] E-mail communication from Chris Collins, deputy director, North Carolina Office of Rural Health and Community Care, November 12, 2011.

[21] E-mail communication from Chris Collins, December 5, 2011.

[22] Medicare Prescription Drug Improvement and Modernization Act of 2003, Public Law 108-173.

[23] A Medicare Advantage plan (like a health maintenance organization or preferrred provider organization) is a health plan choice that people have as part of Medicare. Medicare MA plans (sometimes called Medicare Part C) are offered by private companies approved by Medicare. Joining an MA plan is optional, but people who do join receive all of their Part A (hospital insurance) and Part B (medical insurance) coverage through the plan. Some MA plans may offer extra coverage, such as vision, hearing, dental, or health and wellness programs; and most include Medicare prescription drug coverage (Part D). MA plans are required to follow Medicare rules. Medicare, Gov. Medicare Advantage (Part C), http://www.medicare.gov/navigation/medicare-basics/medicare-benefits/part-c.aspx.

[24] This new MA option was a response to the rapid increase in Medicare costs and the general lack of coordinated care for these vulnerable populations. SNPs also were intended to be used to better integrate Medicare and Medicaid services. Ellen Lukens et al., *Medicare Advantage Special Needs Plans* (Washington, DC: Avalere/ACAP, November 2007).

[25] E-mail communication from Rhys Jones, VP, Medicare policy and product development, Specialty Products Group, Amerigroup Corporation, November 4, 2011.

[26] Ibid.

[27] Ibid.

[28] When first developed, dual eligible SNPs were designed to accommodate existing state waiver demonstration projects to integrate Medicare and Medicaid in Massachusetts, Minnesota, and Wisconsin and to allow additional states to implement integration strategies. B. C. Edwards, S. Tucker, B. Klutz, and L. Flowers., *Integrating Medicare and Medicaid: State Experience with Dual Eligible Medicare Advantage Special Needs Plans*, Research Report (Washington, DC: AARP Public Policy Institute, September 2009).

[29] Centers for Medicare & Medicaid Services (CMS), *State Resource Center: State Options for Designing Dual SNP Contracts with Medicare Advantage Organizations that Adhere to MIPPA Requirements* (Baltimore, MD: CMS, December 2, 2009), https://www.cms.gov/SpecialNeedsPlans/Downloads/MIPPA_State_Contracting_Options_010410.pdf.

[30] E-mail communication from Tashai Atkins, member rights specialist, Community Health Partnership Inc., November 1, 2011.

[31] Ibid.

[32] Ibid.

[33] E-mail communication from Shawn Bloom.

[34] The BBA established the PACE model of care as a permanent entity within the Medicare program and enables states to provide PACE services to Medicaid beneficiaries as a state option. The Medicaid state plan must include PACE as an optional Medicaid benefit before the state and the Secretary of the Department of Health and Human Services can enter into program agreements with PACE providers. Capitated financing allows PACE providers to deliver all services participants need rather than be limited to those reimbursable under the Medicare and Medicaid fee-for-service systems. Medicare-eligible

participants who are *not* eligible for Medicaid pay monthly premiums equal to the Medicaid capitation amount, but no deductibles, coinsurance, or other type of Medicare or Medicaid cost sharing apply. PACE providers are required to assume full financial risk for participants' care without limits on amount, duration, or scope of services.

[35] CMS, Program of All Inclusive Care for the Elderly: Overview (Baltimore, MD: CMS), http://www.cms.gov/pace/.

[36] Ibid.

[37] It took nine years of fund-raising for San Diego's St. Paul's Senior Homes & Services—the program's founding organization—to raise the $4.2 million in seed money needed to start the program. To raise the funding, St. Paul's Senior Homes & Services appealed to San Diego foundations such as the Gary and Mary West Foundation, the Archstone Foundation, and the Price Family Charitable Fund. In addition, annual fund-raising galas were hosted. The $4.2 million was used to finance the purchase of the building that is now the PACE center and clinic, and to hire staff. The program was required to have the following staff in order to pass the readiness review that would enable it to open its doors: a medical director, registered nurses, a home care nurse, a center director, a marketing director, enrollment specialists, a day center manager, a physical therapist, and an occupational therapist. E-mail communication from Amanda Gois Dunkin, marketing director, St. Paul's PACE, San Diego, California, August 8, 2011.

[38] According to the program's marketing director, as of March 2011, St. Paul's PACE has reduced participant hospitalizations by 69 percent. The program attributes the reduction in hospital visits to hands-on medical management, medication management therapy, and daily observation. The program costs the state 13 percent less than the cost of placing a person in a nursing home, which is where these people would be without PACE intervention. A recent study conducted by St. Paul's compared Tenitti scores upon enrollment to the scores 12 months after enrollment. The study found that people who were receiving physical therapy demonstrate a 21 percent improvement in their gait and are less likely to experience falls. E-mail communication from Amanda Gois Dunkin.

[39] The St. Paul PACE program reports to the Long-Term Care Division of the California Department of Health Care Services (DHCS) and CMS, both of which conduct annual surveys to ensure that state and federal regulations are complied with. In addition, DHCS sends a team of nurses to the center on a monthly basis to review medical records, approve new participants, and renew participants who are due for an annual renewal. E-mail communication from Amanda Gois Dunkin.

APPENDIX A. PROJECT ADVISORY COMMITTEE

Shawn M. Bloom
President and CEO
National PACE Association

Rich Brigewatt
President, National Health Policy Group
Chair, Special Needs Plan Alliance

Chris Collins
Deputy Director
North Carolina Office of Rural Health and Community Care
Assistant Director, Division of Medical Assistance-Managed Care

Pam Parker
Director
Minnesota Senior Health Options
State of Minnesota
Department of Human Services

Tork Wade
Executive Director
North Carolina Community Care Network

APPENDIX B. FOCUS GROUP DISCUSSION GUIDE

> *Participants in the focus groups could be a mix of dual eligibles and family members of dual eligibles who are too frail to attend. For this reason, questions in the guide are framed in terms of their own experiences or the experiences of their "loved one" who they care for.*

I. Welcome

Moderator Introduction

Description of the Project

"I am here this afternoon/tonight to discuss health care issues with you. This is part of a national study exploring different kinds of health plans and how they work for people who receive both Medicare and Medicaid. You do not need to be an expert on health care or these programs, I just want to hear about your experiences and feelings about your care or a loved one's health care. I am conducting 10 groups like this in different parts of the country, and I will write a report after I finish these groups."

Ground Rules

➢ Your names will not be used in my report.

➢ We are tape recording/videotaping the discussion.

➢ I have colleagues behind the mirror.

➢ They may send in notes during the discussion.

➢ I need you to speak one at a time because of the audiotape.

Participant Introductions

➢ Name

➢ Whether you are a caregiver for someone with Medicaid/Medicare or you receive Medicaid/Medicare

➢ How long you have received Medicaid/Medicare

➢ Describe kinds of health care needs you have currently

II. Satisfaction with Current Care

Overall, how do you feel about your health care these days? I am talking about everything from your doctors to the services you get to the costs that you pay.

➢ Overall, are you happy with your care?

➢ What are you most happy with?

➢ What are you least happy with?

How do you feel about Medicare?

How about Medicaid—how do you feel about that program?

Let me ask you specifically about the doctors you see. If you see multiple doctors, tell me about them. Are you satisfied with each?

How about the health plan you are enrolled in—how satisfied are you with the benefits that are covered?

How about the costs you pay (if any?)—are they reasonable?

III. Choosing Your Health Plan

Tell me, how did you choose your current health plan?

What is the name of that plan?

What factors did you consider most when choosing this plan? (Listen for…)

> ➢ Keeping my doctor
> ➢ My doctor suggested I enroll
> ➢ This plan has a good reputation
> ➢ I have been in this plan for many years and did not want to change
> ➢ This plan had features I really liked

Have you been enrolled in the plan for a couple of years or is this a new plan? If so, how long?

Were there other health plans you could have chosen? Do you recall what those were?

Why did you not choose those options? What didn't you like about those other options?

Do you remember any details about how your plan is different from those others? If so, please tell me some of the differences.

Do you feel you made some trade-offs when you chose your current plan? In other words, did you feel like you had to give up anything to enroll?

(You mentioned that…) keeping your same doctors was an important factor in the decision. Please tell me how you feel about keeping your doctors? Why is this so important?

Could you ever imagine choosing a plan that does not include your doctor? Why/why not?

What features would a health plan need to have in order for you to consider changing your doctors in order to enroll in that plan?

IV. Challenges

Please tell me, what kinds of challenges do you face with your one's current health plan?

Do you ever face challenges with and of the following? Please tell me if some of these are not applicable to your specific health plan.

➢ Dealing with different ID cards—Medicare, Medicaid, your health plan card? If so, please tell them about this.

➢ Confusion over what benefits are covered and which of your plans covers these services? If so, please tell me about this.

➢ Having multiple health care providers (doctors, nurses, social workers) who do not communicate with each other? If so, please tell me about this.

➢ Decisions about your care are made without considering all of your health needs—for example, treating a specific health condition without considering other medications you may be taking, other conditions you might have? If so, tell me about this.

➢ Very little coordination between the hospital discharge process and the kinds of services you needed once you are home. If so, please tell me about this.

➢ Limited choice in doctors.

➢ Confusing claims and fees.

➢ Could not get services you and your doctor wanted because they were not covered by your plan.

➢ Of these challenges we just discussed, which has been the most difficult for you? Please explain.

➢ On another note, do you know if your health plan has an appeals process? Have you ever used this process? If so, please explain.

V. Transitions

Have you been in a hospital in the last two years? If so, can you tell me about this experience?

I am interested in learning more about the discharge process. How was that process?

Where did you go after leaving the hospital—a skilled nursing facility, a nursing home, or back to you own home?

During this process, was there a health care provider—a doctor, nurse, or social worker—overseeing your care? If so, how was that?

Once you were at home, did any doctors or other providers follow up with your care? Tell me about this.

Did you know how to care for yourself once you returned home?

➢ What challenges did you face?

➢ What help did you need but not receive? Explain.

VI. Communication/Coordination

I know we touched on this issue of communication with your doctors and other health care providers, but let me probe more on it for a few minutes.

➢ How satisfied are you with the communication you have with your various doctors?

➢ Do you feel you have enough time to ask questions during office visits?

➢ Do your health care providers follow up with you after visits around different care issues? Should they?

➢ Do you feel these providers are up-to-date on everything that is going on with you?

➢ How about the communication between your various providers—how satisfied are you with that?

➢ Do your doctors talk to one another about your care? Should they?

➢ Do your doctors generally know what other medications you are currently taking?

➢ Do your health care providers ever consult with each other about your care plan?

➢ Do you feel these providers are coordinating your care?

➢ Or do you feel this job of coordinating falls more to you to do?

Talk about your medical files. Do your different doctors have your up-to-date medical files?

➢ Are you responsible for making sure each of your doctors has your medical history?

➢ Do your providers keep your information electronically as far as you know—like an electronic medical record?

Have you ever experienced a miscommunication with one of your doctors around your health? Received a wrong medication? Been told different things about how to care for your condition by different doctors?

➢ If so, tell me what happened.

➢ Were there negative health effects as a result of this problem?

Do you have anyone who helps coordinate your health care? Is that person a doctor? Nurse? Social worker? If so, how do you feel about this?

➢ If not, do you wish you had more help coordinating your care—making sure your health information is shared between providers, doing follow-up when you leave the hospital or after a doctor's visit, helping make sure there are no errors in the care you receive?

➢ Do you know if your health plan covers that kind of help now? If so, is that a reason you chose it – to get that kind of coordination?

VII. Reactions to Features of Integrated Models of Care

There are different kinds of health plans available to people who are enrolled in both Medicare and Medicaid. I would like your feedback on some features of these different plans to see if you like them or not. In some cases, these may be features of the plans you are currently in. If that is the case, I would like to hear how you feel about this feature and if it is important to you. After looking at each of these, we will discuss them one at a time (HANDOUT).

- ➢ Having just one ID card to use every time you need health care or medications.

- ➢ One set of benefits that are covered without you having to know which program covers which benefits.

- ➢ A single team of health care providers and a point person to help you coordinate your care.

- ➢ The approach to care is focused on the whole patient and puts you, the patient, at the center of the care. That means all of your needs are considered when making care decisions.

- ➢ More home and community-based services are covered to help keep you in your home as long as possible.

- ➢ There is an emphasis on improving your "transitions" between different care settings—like between a hospital and your home—so that you have the care and services in place so that you have better outcomes.

- ➢ There is a patient advocate attached to your plan to fight for you and make sure you get the care you need.

- ➢ There is a comprehensive assessment of your care needs once you enroll in the plan and a personalized care plan is developed for you to make sure you get all of the services and supports needed.

- ➢ Family caregivers are involved from the start.

- ➢ The plan makes effective data-sharing and updated communication methods available so that your health information is more easily shared among your providers, and with you.

Which of these features do you like most? Why?

- ➢ Would you like these features to exist in your current health plan?

- ➢ Do they already? If so, tell me your experience with these features.

- ➢ Which of these features are least important to you? Why?

- ➢ Are any of these features appealing enough to you that you would consider changing health plans to obtain them? Which ones?

- ➢ What if some of these plans require you to use their own doctors—would you ever considering changing your doctor? Explain.

VIII. Closing

If you could make changes and improvement to your/loved one's health care, what would those be?

Thank you. Have a nice evening.

APPENDIX C. CHARACTERISTICS OF FOCUS GROUP PARTICIPANTS

Characteristics of New York Focus Group Participants

GENDER	RACE/ETHNICITY	HEALTH CONDITIONS	
10 Women 6 Men	3 African American 13 White	Cancer Diverticulitis Heart conditions Back and knee problems	Diabetes Osteoporosis High blood pressure Parkinson's disease

Characteristics of North Carolina Focus Group Participants

GENDER	RACE/ETHNICITY	HEALTH CONDITIONS	
9 Women 6 Men	10 African American 5 White	Chronic obstructive pulmonary disease Autoimmune disease Lupus High blood pressure	Scoliosis Asthma and emphysema Diabetes Joint problems

Characteristics of Partially Integrated SNP Focus Group Participants

GENDER	RACE/ETHNICITY	HEALTH CONDITIONS	
6 Women 6 Men	9 African American 3 White	Chronic pain High blood pressure Back problems Gastrointestinal problems	Blindness Asthma Insomnia Cancer

Characteristics of Fully Integrated SNP Focus Group Participants

GENDER	RACE/ETHNICITY	HEALTH CONDITIONS	
10 Women 9 Men	All (19) White	Back pain Memory loss Joint problems Stroke	Diabetes Blood clots Cancer

PACE Focus Group Participants

GENDER	RACE/ETHNICITY	HEALTH CONDITIONS	
9 Women 6 Men	11 White 1 African American 2 Latino 1 Asian	Diabetes Joint problems Anemia Kidney disease	Heart conditions Osteoporosis Mental disease Macular degeneration