

University of Maryland Center on Aging

*Medicare/Medicaid
Integration Project*

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**Consumer Involvement in Managed Care Programs
Serving Persons Dually Eligible for
Medicaid and Medicare**

A Technical Assistance Paper of
**The Robert Wood Johnson Foundation
Medicare/Medicaid Integration Program**
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The Medicare/Medicaid Integration Program

The purpose of The Robert Wood Johnson Foundation Medicare/Medicaid Integration Program (MMIP) is to end the fragmentation of financing, case management, and service delivery that currently exists between Medicare and Medicaid. States will be provided with grant support and technical assistance in their efforts to restructure the way in which they finance and deliver acute and long-term care. Technical assistance will focus on those states that have been awarded grants, but not be limited to grantees. It is recognized that other states and initiatives can benefit from this help. This paper represents one such effort.

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More information about the MMIP can be obtained from the following locations:

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Executive Summary

By seeking and using consumer input, planners and managers implement programs that succeed in meeting consumer needs, obtain needed feedback on programs quickly, and have opportunities to educate and create buy-in.

Meaningful consumer involvement requires energy and dedication to ensure that input is gathered from a variety of dually eligible consumers and family members on an ongoing basis, is used as appropriate, and is “fed back” to consumers to show how it has been used. The experiences of five states striving to meaningfully involve consumers in programs with high percentages of dually eligible people have driven this report.

Steps to Meaningful Consumer Involvement:

1. Clarify specific goals in involving dually eligible consumers and the criteria for the input mechanisms needed to meet those goals.
2. Determine the potential target populations to be involved. The State officials interviewed think in terms of whom they want the program to serve and seek to get that target population involved. Therefore, while their consumer involvement efforts have included people who are dually eligible, they have not intentionally sought the input of different dually eligible subgroups.
3. Choose the most appropriate input mechanisms to meet the goals.
4. Determine the State’s role.
5. Work out logistical issues, including what questions to ask, which issues to include on agendas, and when/where/for how long structured face-to-face interactions will occur.
6. Develop recruitment methods, stressing that consumers participating will not suffer reprisals for their input. Work with people “in the know” (advocates, health plans, and providers) to identify dually eligible individuals to involve.
7. Maximize meaningful participation by minimizing barriers related to dually eligible people’s possible impairments. Minimizing “managed care speak” and consumer fears will also get more consumers involved. Other considerations:

Surveys - Word questions so that answers can guide decision-making. Obtain responses from as many as possible, through such means as notices asking for participation, toll-free phone lines for consumers with questions, and follow-up letters/phone calls.

Focus groups - To foster participation among all participants, planners should limit the number in each group, keep groups homogenous, be sensitive to things that may cause the “chilling effect” (e.g., tape recording the session or having the group facilitated by a State or health plan official), offer incentives, and hold groups at places used by dually eligible consumers.

Public forums - Publish adequate notice. Hold forums in environments familiar to consumers to encourage more positive meetings. Allow time for public comment, as well as for the State to convey information.

Advisory committees/workgroups:

- Hold meetings in different locations/times to increase accessibility.
- Educate members on the complexities of Medicaid, Medicare, managed care, and on realistic expectations for the proposed program.
- Make sure members are clear about their role.
- Report back during the course of each meeting on issues raised at prior meetings.
- Use tangible ways (e.g., transportation reimbursements, food at meetings, small stipends, gift certificates) to demonstrate that you value consumer input.

Complaints/grievances - Implement methods that help take the fear and confusion out of complaining, such as toll-free hotlines and ombudsman programs. Make accommodations for consumers who use TDD or other adaptive communication technology to help some dually eligible people. Have draft documents explaining grievance processes reviewed by advisory committees to ensure that consumers will find them useful.

8. Provide feedback to the groups involved on an ongoing basis and to the public at large (e.g., through report cards).

Using Consumer Input

Consumer and advocate input has resulted in states:

- Changing proposed enrollment from mandatory to voluntary.
- Changing the proposed specialty clinic model to a provider network model.
- Modifying the complaints/grievance process.
- Developing risk-adjusted capitation rates.
- Creating more detailed and tighter RFP standards on provider networks, appointment waiting times, referral processes, internal quality assurance procedures, and home health and transportation providers.
- Modifying marketing and enrollment materials to highlight issues important to potential consumers who are dually eligible.
- Developing orientation booklets and resource documents.
- Developing tools for health plans’ internal quality improvement efforts.

Introduction

This paper explores the role of consumers in the development and implementation of managed care programs for persons eligible for both Medicare and Medicaid. Various approaches include considerations with regard to dually eligible consumers.

Who Are We Talking About?

People who are dually eligible are aged, blind or disabled individuals eligible for both Medicaid and Medicare. Individuals gain this dual eligibility in a variety of ways (for more information, see Appendix A). Rather than a homogenous group, they have different incomes and medical needs, of which planners need to be aware. Despite the distinctions, however, many people who are dually eligible have greater health care needs than Medicaid- or Medicare-only beneficiaries, which make involvement in the process more difficult. Planners and managers may have to rely more on family members and other consumer representatives for input.

States serving dually eligible people through managed care are covering new ground. Dually eligible people have frequently relied on different systems and have different issues than populations more traditionally served in either Medicaid or Medicare managed care. Therefore, their input becomes highly significant in creating workable programs.

States Under Study

In October 1997, NASHP staff conducted telephone interviews with officials of six programs in five states (Colorado, Florida, Minnesota, New Jersey and Wisconsin) about their consumer involvement experiences in programs with high percentages of dually eligible consumers. (Most of these programs also sought input from consumers who were not dually eligible.) These states represent a range of approaches to managed care programs that serve dually eligible people (a matrix describing program characteristics and consumer input mechanisms is located in Appendix B). Despite the differences in activities, the input mechanisms used by these states are quite similar.

Six Managed Care Programs Examined	
Colorado	<i>Integrated Care and Financing Project</i> will combine Medicare and Medicaid health, social and supportive services through a multi-disciplinary team. It will begin enrolling in one county in the spring of 1998.
Florida	<i>Long-Term Care Community Diversion Pilot Project</i> will provide acute care, home and community-based long-term care, and when necessary, nursing home care. (The Project is set up as an alternative to institutional care.) The Project will serve dually eligible consumers (only) in 8 cities in 2 areas. The Project's start date is still to be determined.
Minnesota	<i>Minnesota Senior Health Options (MSHO)</i> coordinates all Medicare and Medicaid services (both acute and long-term care) through a single contract with managed care plans. MSHO also has single enrollment, grievance and quality assurance procedures. MSHO only serves consumers who are dually eligible.
New Jersey	Includes people who are dually eligible in the voluntary <i>Medicaid managed care</i> program. The state currently enrolls SSI beneficiaries into Medicaid managed care on a voluntary basis, but plans to make enrollment mandatory in the summer of 1999. While people who are dually eligible will still be voluntary enrollees, more are expected to enroll as a result.
Wisconsin (2 programs)	<p><i>Independent Care (I Care)</i> coordinates primary, acute, and social services for people over age 15 with disabilities through care coordinators. Long-term care is limited; individuals going into community-based waiver programs or long-term nursing facility placements are disenrolled from the program. I Care includes individuals who are dually eligible and individuals who are Medicaid-eligible only.</p> <p><i>Partnership</i> coordinates primary, acute and long-term services for nursing facility eligible people aged 55+ in Milwaukee County, people aged 18-64 with severe disabilities in Dane County, and both populations in two rural counties. Virtually all participants are dually eligible.</p>

Consumer Involvement in Managed Care

Consumer Input - Why Planners & Managers Need It

Program planners and managers achieve several goals by seeking and using consumer input in program design and operation:

- *They implement programs that succeed in meeting consumer needs.* Consumer involvement plays an important role in determining consumer satisfaction, perhaps

the best predictor of plan growth and ultimate success.¹ This may be especially true for people who are dually eligible, since they are generally enrolled voluntarily in managed care.

Discovering consumer needs by going directly to consumers themselves is the most foolproof way of assuring that the proposed program will address these needs. Having consumers participate in determining how to best meet those needs can result in programs with higher satisfaction levels. As Michael Cronin, Director of JRI Health (a division of Justice Resource Institute) in Boston, notes, "With HMOs being given responsibility for more and more — including long-term care, which they know very little about — it's really important to bring in some folks who do know something about long-term care and community-based care — the consumers, the folks who deal with this every day."²

- *They obtain needed feedback on how the program is working quickly.* Although clinical knowledge is also necessary to assess the adequacy of care, many problems in managed care are first recognized by consumers. Moreover, consumers can provide feedback on aspects of care not traditionally measured, but which have an effect on their quality of life. For people who are dually eligible and in need of many non-medical services, such measures are highly significant.
- Useful information from quality assurance mechanisms, such as record reviews or encounter data, is already dated by the time it is produced. Consumer input (particularly through face-to-face forums) allows planners and managers to quickly understand how policies are being implemented at the provider level, and to address problems before they escalate.
- *They have opportunities to educate and create buy-in.* As Catherine Dunham, Project Director of the Robert Wood Johnson Community Health Leaders Program and former Massachusetts official, points out, "Nowadays, you can't get anywhere without a base. [Involving consumers and advocates] is not only the right thing to do; it's the only way to get anything done."³

¹ Schiff, L., and Services, R. "Empowered Patients Buy More Efficient Care," *Business & Health*, 1996, page 35.

² "Consumers at the Table: Inform, Protect & Activate," *Coming of Age in State Health Reform: Taking Stock - Taking Action (10th Anniversary Annual State Health Policy Conference)*. Portland, Maine: National Academy for State Health Policy, August 11, 1997.

³ "Consumers at the Table...."

This good will, in addition to facilitating getting the program off the ground, can also lessen the chances of laws being created which micro-manage the program and may be intrusive or patronizing to its participants.

As an example of the power of good will, Wisconsin's I Care relies on it for new clients. Program staff send brochures to a randomly selected group of potential participants each month, then call to follow up. During the three-month informing period, recipients are encouraged to contact advocacy organizations for their advice about the program.

What Is Meaningful Involvement?

Meaningful consumer involvement requires energy and dedication to ensure that input is gathered from a variety of consumers and their family members, is used as appropriate, and is "fed back" to consumers to show how it has been used. People have different views on what constitutes meaningful involvement, but agree that it includes:

- *Ongoing search for input* - Successful consumer involvement efforts have multiple opportunities for interested consumers to participate at the levels with which they feel comfortable.
- *User-friendly input mechanisms* - Different consumers have different abilities and desires to participate; using a variety of approaches results in greater numbers becoming part of the process. Any method used should be easy for consumers to understand and access if interested, including consumers whose primary language is not English or who have difficulties communicating. Consumers also need to be made aware of ways to participate.
- *Feedback* - If consumers do not feel that they are being heard, they may lose interest in participating. If a particular consumer suggestion cannot be successfully implemented, providing the rationale will let the consumers making the suggestion know that the idea's merit was considered, which will hopefully result in continued good will.
- *Concrete results* - In the most successful consumer involvement efforts, participating consumers see their input being used. This keeps consumers motivated to stay involved and generates needed good will.

When Do You Get Consumers Involved?

Effective consumer involvement efforts start as early as possible in program development. Having consumers and advocates as active participants from the beginning can lead to a greater sense of community good will, as well as important input in assessing needs.

Laying the Foundation

Creating a Consumer-friendly Environment

Effective involvement of consumers who are dually eligible happens in a managed care environment in which individuals feel that their ideas and concerns have weight. Such an environment is enhanced in several ways

Programmatic stress on consumer-driven health. The Wisconsin Partnership Program is a good example of a program stressing the active role of the consumer in health care. State chart reviews of contractors seek: (1) to discover whether there is a system in place to ensure that enrollee preferences, priorities, desires and fears are clearly identified and integrated into plan of care development; and (2) to discover whether the system in place works effectively by showing evidence of meeting 12 indicators, including information provided to enrollees to increase their understanding of possible outcomes of different treatment options, enrollee participation in decision-making about treatment options, and progress toward enrollee goals.⁴ Partnership used monthly contractor meetings to foster a consumer-centered culture among its contractors.

All Partnership enrollees have care coordination teams. Care coordination, linking network and out-of-network medical and social services, is an integral component of any program integrating acute and long-term care for consumers who are dually eligible. Coordinators typically promote involvement of consumers in health care decisions in several ways:

- They assist consumers in navigating the health delivery system and provide one-on-one health care education.

⁴ Bowers, Barbara, Esmond, Sara, and Lutz, Barbara. *Wisconsin Partnership Program: Protocols for Annual Quality Improvement Reviews*. Madison, Wisconsin: Department of Health and Family Services, Bureau of Health Care Financing, May 1997, page 7.

- They highlight the roles of consumers and family members in making decisions regarding care. (Partnership training for care coordination teams includes a module designed to increase interviewing skills to determine consumers' goals and preferences, family system, and relationship with providers.⁵)
- They can also serve as conduits of information between consumers and the plan, since the relationships formed may make the consumer feel more comfortable in discussing concerns and issues. Such an avenue for providing input may seem like the only one available to many medically fragile consumers who are dually eligible.

Managed care plan commitment to quality care.⁶ An effective health care delivery system for individuals who are dually eligible seeks to achieve a number of consumer-centered outcomes:⁷

- Quality of life and autonomy; highest possible level of function
- Consumer satisfaction
- Participation in care decisions
- Preservation and support of natural (and non-medical) supports
- Cost-effective delivery
- Immediate feedback mechanisms.

State planners may want to assert in the RFP that they will consider evidence of such consumer-centered outcomes as part of the evaluation of potential contractors.

⁵ Bowers, Barbara. *Building Health Care Systems for People with Chronic Illness: Quality Research, Year II - Annual Report*. Madison, Wisconsin: University of Wisconsin School of Nursing, September 30, 1996, page 165.

⁶ The following three topics were taken from Bonnyman, Gordon, *Managed Care and Children with Special Needs: Consumer Leadership and Participation*. Princeton, New Jersey: Center for Health Care Strategies, Inc., July 1997, page 6.

⁷ Fitzgibbons, Dennis. "Consumer Involvement/Managed Care Issues" session, *Contracting for Medicaid Managed Care for Elders and Persons with Disabilities* seminar. Washington, D.C.: National Academy for State Health Policy, January 29, 1997.

Administrator openness. The perceived attitude of the planner/manager regarding consumer involvement may be more significant than mechanisms used to gain input.

- The Director of Minnesota Senior Health Options stated that her “past life” as a consumer advocate increased the trust level among advocates and dually eligible consumers that their concerns would be heard, and made for a smoother transition of participants from fee-for-service to managed care.
- An attendee of I Care’s Advocate Advisory Meetings reported that the presence of the CEO and care coordinators increased attendees’ confidence that their input would be incorporated into quality improvement action plans.⁸

Some states have designated staff liaisons (including ombudsman staff) to consumers and advocacy groups as a way to concretely demonstrate such openness. Suggestions for making this liaison effective in working with dually eligible consumers include:

- Advertising at nursing facilities, rehabilitation centers, meal sites, senior centers or senior housing complexes
- Hiring staff familiar with gerontologically- or disability-related issues (done by both Minnesota and Colorado)
- Consumers in nursing facilities may fear contacting such an office, if they do not have access to a phone in an area where they can speak privately, or if they believe the addresses on outgoing mail may be noticed by facility staff. To combat this, liaison staff may want to visit facilities to speak with residents first-hand.

Organized, informed consumers. The education of consumers has frequently been recognized as an essential link to ensure the success of other consumer involvement mechanisms.⁹ Catherine Dunham, Project Director of the Robert Wood Johnson Community Health Leaders Program and former Massachusetts official, notes, “Many consumers are invited [onto advisory committees and other groups] as individuals. They’re smart people, but they don’t have a prayer if they don’t have the level of policy expertise needed. They’re disadvantaged by not even knowing the language of the discourse that’s going on at a furious pace and that is supposedly going on with the

⁸Human Services Research Institute. *Wisconsin Special Care Initiative Project: Evaluation of Independent Care (I Care), Quality Assurance Substudy Final Report.* August 30, 1996, page 14.

⁹ Perkins, Jane, Olson, Kristi, Rivera, Lourdes and Skatrud, Julie. *Making the Consumers’ Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction.* Chapel Hill, North Carolina: National Health Law Program, Inc., December 1996, page 81.

benefit of their expertise and knowledge.”¹⁰ In addition to educating consumers who are dually eligible regarding the complexities of Medicaid, Medicare and managed care, a key to their involvement is alleviating the fear that they risk retaliation by expressing less than complimentary views.

Effective consumer involvement does not just happen; such participation is usually more effective where there is an organizational infrastructure, in the form of a consumer group or coalition, to sustain it.¹¹ Such groups may facilitate consumer involvement by providing education, moral and emotional support (which consumers need to keep from being intimidated by the professionals and policymakers with whom they are interacting¹²), and financial assistance to consumers attending meetings. However, most groups have extremely few technical and monetary resources. As Catherine Dunham of RWJ states, “One of the romantic notions of the market system is that it will be driven by consumers, and the ability to participate in these complicated health systems and political systems will just burst out of these communities. Everyone else at the table has an organization that pays them to go to meetings, does research, prints up materials, and helps them figure out if the proposed changes to regulation or law are going to hurt or help them.”¹³ June Gross, Director of the Parent Professional Advocacy League, the Massachusetts chapter of the Federation of Families for Children's Mental Health, adds, “We're supposed to monitor this incredibly complex, sophisticated, multinational, corporate system — with what?”¹⁴

Consumers who are dually eligible may be at a disadvantage due to the lack of consumer groups specifically geared to their needs. Although advocacy groups such as the American Association of Retired Persons (AARP) speak for older adults, a minority of their constituents will have low enough incomes to qualify for Medicaid, and they do not speak for non-elderly disabled consumers with dual eligibility.

¹⁰ “Consumers at the Table....”

¹¹ Bonnyman, Gordon. “Consumers’ Role in Developing and Directing Medicaid Managed Care for People with Special Needs,” *Health Strategies Quarterly*. Princeton, New Jersey: Center for Health Care Strategies, Inc. Volume 1, Issue 3, Fall 1997, page 2.

¹² Ibid.

¹³ “Consumers at the Table....”

¹⁴ “Consumer and Family Involvement: How to Get It, How to Use It Effectively,” *Behavioral Health in Medicaid Managed Care: A “How To” for State Policymakers*. Portland, Maine: National Academy for State Health Policy, August 12, 1997.

Financial resources can help create and sustain the infrastructure needed to keep dedicated volunteers organized, pay the cost of newsletters to educate consumers, and defray transportation costs for consumers to attend meetings. Technical resources include training sessions, written materials, or help understanding contracting and legal issues.

- During the development of the StarPlus program, which integrates acute and long-term care and voluntarily enrolls consumers who are dually eligible (as well as Medicaid-only consumers), the Texas Planning Council on Developmental Disabilities offered a competitive grant to educate consumers with disabilities of all types about managed care, and to educate health plans and providers about issues of importance to consumers with disabilities. This grant (approximately \$100,000 over two years) was awarded to “HealthCare Matters!,” a consortium of disability groups composed of Texas Advocacy, Inc., Texas ADAPT, and Texas Respite Resource Network. At the encouragement of the state Health and Human Services Commission, the Medicaid agency (which is implementing StarPlus) came to a cooperative agreement with HealthCare Matters! to provide in-kind support. The Medicaid agency also dedicated a portion of its Robert Wood Johnson grant (awarded to help implement StarPlus) to HealthCare Matters!.
- The New York Office of Mental Health funded the Mental Health Recipient Empowerment Project (MHREP), a grassroots effort aimed at creating a statewide consumer movement.
 - In 1988, MHREP’s sole staff person met with over 400 consumers in approximately 30 small groups held at mental health programs around the state. Included in these meetings were members of two active recipient-run programs. Consumers were also offered scholarships to participate in advocacy training offered by The Alliance, a recipient-run advocacy group in Syracuse.
 - From 1989 through 1995, MHREP ran statewide consumer conferences, free to all participants. Approximately 200-250 consumers participated annually.
 - Since 1996, annual two-day conferences have been held in each of the state’s five regions, in order to reach more consumers. Over 100 participate in each conference. All faculty are consumers.

Darby Penney, Director of the Recipient Affairs Office of the Office of Mental Health, described the grassroots effort as “very successful — ten years later, we have a steady supply of people who have been doing policy work and who understand the issues.”¹⁵

¹⁵ “Consumer and Family Involvement...”

- The National Health Law Program is sponsoring projects in five states — California, Kentucky, New York, Ohio, and Washington — in which state officials and advocacy groups focusing on families and children are developing processes for increased consumer involvement. Planning grants were awarded to consumer organizations to defray the costs of consumers attending meetings.

Steps to Meaningful Consumer Involvement

Step 1: Define the Goals

In order to get the most from a consumer input mechanism, planners and managers will first want to be clear about specific goals in involving consumers and what meeting those goals will involve:

Goals for Consumer Involvement	
<i>Goal</i>	<i>Criteria for Meaningful Input Mechanism</i>
Assess needs	Wide range of dually eligible consumers involved Information “snapshot”
Work out the details on how best to meet needs	Smaller, ongoing representative group (consumers and advocates) that can be educated early on Large numbers of consumers and advocates with awareness and access (if interested) to draft proposals close to program launch
Build good will	Well-advertised opportunities to interact with target populations and their representatives
Assess how program is meeting needs, fine tune	Wide range of dually eligible consumers involved (including those who have chosen not to participate in the program as well as those who have) Information “snapshots” Ongoing opportunities for individuals’ problems/issues to be heard

Step 2: Determine the Potential Target

Determining who should be asked to be involved is another critical early step, and can be challenging for programs designed to enroll consumers who are dually eligible.

State officials interviewed do not think of dually eligible people as a separate group from Medicaid-only beneficiaries. Instead, they think of whom they want the program to serve and seek to get that population involved. Therefore, while their efforts have included people who are dually eligible, these officials have not intentionally sought the input of different dually eligible subgroups.

Groups targeted for involvement include:

- Wisconsin conducts satisfaction surveys with both I Care consumers and family members involved in the consumers' treatment.
- Wisconsin's Partnership Program requires contractors to recruit individuals who have the same health care needs as enrollees for consumer advisory groups. These individuals do not fear possible reprisals as enrollees may.

Step 3: Choose Mechanisms

Once planners/managers are clear about the goals for involving consumers and criteria for obtaining meaningful information among the target population, they can determine the most appropriate mechanisms to meet these goals. Many states use several approaches. A multi-pronged approach increases the chances that multiple goals are achieved, and that the data gathered represents the views of a wide variety of people.

Needs assessment surveys/interviews. For the purposes of this report, surveys are defined as relying predominantly on close-ended (yes/no, fill-in-the-blank, check-the-box-that-closest-fits, short answer) questions; interviews rely on open-ended ("What do you think about _____?" "Describe your experiences around _____.") questions. Surveys can provide input from large numbers of beneficiaries and their family members who may be affected by the proposed program. Interviews can provide more detailed information, although usually from a smaller segment of the targeted population (due to resource constraints).

*Involving Dually Eligible Consumers through
Needs Assessment Surveys/Interviews*

Surveys and interviews allow planners to obtain input from dually eligible people who are unable to attend public forums due to health problems.

Given the small proportion of those who are dually eligible among Medicaid- or Medicare-eligible consumers, obtaining an accurate picture of their needs may require over-sampling.

Focus groups can provide a sense of the issues and concerns of the proposed beneficiary group quickly, and without the expense that a large-scale survey entails. One individual's comments may spur ideas among the other participants that would not have been considered in one-on-one interviews.

*Involving Dually Eligible Consumers through **Focus Group***

Holding focus group meetings at facilities used by consumers who are dually eligible, such as nursing facilities, rehabilitation centers, meal sites, or senior housing complexes, will increase their participation.

Public forums are commonly used by planners. Texas staff reported that as they have become more sophisticated in launching managed care programs, one lesson learned has been to hold public meetings to discuss what managed care will look like and respond to questions and concerns. In addition to educating potential consumers and their representatives about the program, public forums provide a quick way for planners to get a sense of concerns regarding the proposed program. By holding forums in a variety of organizations, planners and managers can speak directly with a wide range of dually eligible people who may be affected by the proposed program or changes in an existing program.

*Involving Dually Eligible Consumers through **Public Forums***

Frail people who are dually eligible may be unable to attend, depending on the forum's location.

Holding meetings in facilities used by consumers who are dually eligible, may be effective in increasing participation.

Meetings can be held on a regular basis, or as requests are made.

- *Regularly scheduled meetings*, with no set membership, give planners and managers ongoing opportunities to interact with consumers and advocates. These meetings allow planners to “keep their finger on the pulse”, getting a sense of how different aspects of the program will be received as they are designed or modified. Holding regular meetings lets consumers and advocates know that they have an ongoing forum to express concerns. Additionally, these meetings can serve as educational forums.
- *Ad hoc meetings* can be held with individuals or groups of consumers and advocates. Problems can be raised through ad hoc meetings very quickly after being identified by consumers. These meetings also provide opportunities for one-on-one education. However, the consumer, family member or advocate needs to know whom to call to set up a meeting or where to look to determine if a meeting is scheduled, and consumers or family members may be too intimidated to call State officials.

*Involving Dually Eligible Consumers through **Meetings***

Consumers who are dually eligible may be physically unable to meet in person with State officials, and may not have access to a phone in an area where they can speak privately.

Consumers who are dually eligible, lacking an organized advocacy group, may not get their specific needs heard when meetings are primarily held with advocates.

Advisory committees and work groups are a common method for gaining ongoing consumer input into program design. An ongoing committee with set membership can

be an extremely valuable source of input on each program element as it is designed. Once programs are operational, advisory committee members may be one of the state's or plan's first resources in fine-tuning and in identifying problems before they escalate.

*Involving Dually Eligible Consumers through
Advisory Committees/Workgroups*

Recruiting participants may be a challenge, given the health issues faced by many dually eligible people. It may be more likely that family members participate.

Involvement on governing bodies Consumers participating on governing bodies go beyond reacting to policy to shaping the policy agenda. However, few states require health plans to include consumers on their boards. States considering requiring this may want to consider the following:

- One consumer will not effectively speak to the variety of needs of all consumers.
- A consumer board member must be clear about who he/she represents, to minimize confusion, both for the consumer him/herself, and for other members of the governing structure.
- How to support and educate the consumers involved is a complicated issue (see "Organized, informed consumers" section on page 7).

*Involving Dually Eligible Consumers through
Involvement on Governing Bodies*

Like advisory committees, recruiting dually eligible consumers may be a challenge, given health issues.

Written comments on draft documents/formal requests for information (RFIs).

While many states report soliciting and receiving written comments on drafts, fewer use formal RFIs. Feedback on these written sources can come from a variety of sources,

including responses in writing and orally during public forums. Seeing drafts in advance gives consumers time to digest information before formulating responses. On the down side, consumers may be intimidated by the language of the documents.

*Involving Dually Eligible Consumers through
Written Comments on Drafts/Formal RFIs*

Consumers who are dually eligible and unable, due to health reasons, to attend meetings can still provide feedback, particularly if they do not need to be present at forums to do so.

Responses will be more common from advocacy groups than from individual consumers. Without organized advocates, dually eligible consumers may be at a disadvantage.

Satisfaction surveys. HCFA requires states to periodically assess consumer satisfaction with managed care programs. States either administer satisfaction surveys themselves, use an independent entity, and/or require plans to do so. Issues frequently covered include accessibility of services and providers, quality, and choice.

Consumer satisfaction surveys can provide an across-the-board picture, whereas focus groups, participation on committees, and tracking grievances describe the experiences of relatively few consumers. Consumer responses can be given anonymously, so fear of reprisal is lessened.

Consumer satisfaction surveys also have their drawbacks. Few satisfaction surveys have been validated as reliable, limiting their use as decision-making tools.¹⁶ Such surveys can be costly, both financially and in the staff time needed to design, conduct and analyze the results.

¹⁶ Bradley, Valerie, President, Human Services Research Institute. "The State of the Art in Quality Measurement for People with Disabilities" plenary session, *Managed Care and Disability: Consumer Needs and Quality Measures* conference.

*Involving Dually Eligible Consumers through **Satisfaction Surveys***

Getting a clear picture of the experiences of people who are dually eligible may require over-sampling, or may not be statistically valid.

Consumers who are dually eligible will have input on areas (such as nursing facilities) that larger populations will not.

Satisfaction surveys are dependent on respondents' memories. Dually eligible consumers in need of long-term care services may be cognitively impaired and unable to answer these questions. Visual or hearing impairments may also complicate obtaining responses through such surveys.

Complaints and grievances. All states require health plans to establish procedures for handling both formal and informal complaints/grievances, as well as operating their own systems for enrollees to express dissatisfaction.¹⁷ Monitoring complaints/grievances can quickly identify problems before they become widespread and may also illuminate areas where greater consumer education is needed.

*Involving Dually Eligible Consumers through
Complaint/Grievance Processes*

As has been mentioned, residents of nursing facilities may be fearful of retaliation, as their ability to grieve in private may be limited.

Cognitive or other disabilities may complicate this process.

Consumers needing long-term care may not have the energy to pursue the complaint/grievance process.

Step 4: Determine Your Role

¹⁷ For more information about these procedures, see *Snapshot of Medicaid Managed Care Ombudsman and Grievance Procedures* by Jane Horvath and Neva Kaye. Portland, Maine: National Academy for State Health Policy, November 1996.

Once the mechanisms for consumer involvement have been chosen, state planners and managers next determine how involved the agency will be in designing and implementing these mechanisms.

Hands-on. In most states, at least some of the consumer involvement activities are implemented by the agency itself. State agencies use a hands-on approach for a number of reasons: it enables them to cultivate relationships and good will; they may be seen as more neutral (and trustworthy) than health plan personnel and have the authority to make changes to proposed or operational programs, so consumers may be more willing to participate and more forthcoming in their comments. The downside to direct involvement are the time and staffing resources required.

(Note: Most of the steps listed below assume that the State takes a hands-on approach; however, even if the agency chooses not to be directly involved, planners will want to monitor the entity that conducts the involvement mechanisms in order to assure that these methods produce consumer input that is meaningful for basing decisions upon).

Requiring the contractor to obtain consumer input. Most of the programs examined for this report were small enough to have few contractors. Several contractors were nonprofit agencies. Under such circumstances, the contractor may be closer to the target population(s). Having contractors involved in gaining consumer input may also work to build relationships empower consumers. However, consumers may feel that the health plan is “going through the motions” required, without any real interest in their opinions and issues.

Some of the ways states have used this contractor requirement successfully include:

- *Needs assessments* - Wisconsin Partnership officials required the community-based organizations interested in becoming contractors to conduct needs assessments as part of their proposals. The assessments involved surveys of the proposed beneficiaries (adults with significant physical disabilities and frail older adults; overwhelmingly individuals who were dually eligible) who were currently receiving services from these contractors.
- *Advisory committees/workgroups* - Both Colorado and New Jersey require contracted health plans to have consumer committees advise on general Medicaid managed care issues (plans are not mandated to include dually eligible consumers). Each State checks committees' lists of participants to determine whom each represents, and monitors committee meeting minutes to ensure the committees are

active. Colorado follows up with the health plan on issues raised in the minutes.

Wisconsin's Partnership Program requires its four contractors to include consumer representatives on their Grievance, Marketing and Ethics Workgroups. State officials review meeting minutes as part of the yearly audit.

- *Involvement on governing bodies* - Minnesota requires enrollee participation on health plan governing boards.

Partnership, Inc. is an umbrella organization of the four contractors participating in Wisconsin's Partnership Program. The five-member board is composed of the CEO/president of each contractor and a consumer advocate.

- *Satisfaction surveys* - Many states require health plans to conduct these surveys and to use the results as part of internal quality assurance. In Wisconsin's Partnership program, the contractors routinely survey their enrollees on specific needs and issues. Identifying issues on which to conduct surveys happens in daily care coordination team meetings.
- *Complaints/grievances* - States require that plans track and report on disenrollments and status and types of complaints/grievances as part of their quality monitoring.

Partnering with the contractor is less common scenario among states. On the one hand, such a partnership may combine the populations expertise of the contractor (if it focuses on a smaller, more specialized population) with the authority of the State. On the other hand, it may diminish the perceived neutrality of the State.

Wisconsin's Partnership Program is conducting an enrollment study to determine the factors which drive the individual's decision to enroll/not enroll/disenroll. Staff from the State and the contractors will attempt to contact everyone who has received information on Partnership, and to conduct face-to-face interviews with all who agree to participate.

Utilizing an outside entity. Employing outside research firms or academic institutions (with strong consumer research credentials) means that the input mechanism is designed and implemented by expert staff, so planners can feel more confident in the results. An outside entity would definitely be perceived as neutral by consumers, so they may be more forthcoming. However, cost is an issue. For example, using

consultants to gather and run three focus groups for plan start-up research in a market of about 50,000 to 100,000 eligibles can cost about \$20,000.¹⁸

Examples of states successfully using outside entities include:

- *Surveys:*
 - Wisconsin officials hired the University of Wisconsin-Madison School of Nursing to research the long-term care needs of dually eligible consumers, prior to designing the Partnership Program.
 - New Jersey contracted Health Visions, Inc. and Philadelphia Health Management Corporation, independent non-profit research and planning agencies, to conduct a telephone survey among the SSI population enrolled in managed care (New Jersey also requires plans to conduct satisfaction surveys).
 - Wisconsin's I Care program uses Human Services Research Institute, an independent research firm, to conduct consumer surveys, as well as conducting its own.
- *Planning meeting* - In planning I Care, a Medicaid Working Group conference was held for key stakeholders to define and address issues in planning a managed care program for high-cost beneficiaries. Participants included program planners, advocates and consumers.
- *Satisfaction/grievance resolution* - Texas will contract quality monitoring for its Medicaid managed care program to the team of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and FMAS Corporation (in Rockville, Maryland). Proposed responsibilities of this team will include conducting consumer satisfaction surveys and resolving consumer grievances.

¹⁸ "Enrollment low? Disenrollment high? Just getting started? Focus group may help", *Public Sector Contracting Report*. Marietta, Georgia: National Health Information, L.L.C. Volume 3, No. 10, October 1997, page 154.

Step 5: Work Out Logistics

State agencies wanting to be directly involved in obtaining consumer input have a series of details to consider.

Regardless of the mechanism used, an important logistical issue to consider at this time is: what happens to the data once it has been gathered? Thinking now about the processes for analysis and use will save planners and managers headaches later.

Logistical Issues: **Surveys (mostly close-ended questions)**

What questions will provide the most useful information?

What wording will be understood by most people?

Will the survey be mailed, conducted over the telephone, or conducted in person? (Mail surveys typically have a low response rate; telephone or in-person surveys may result in selection bias. This bias may be a particular problem with consumers who are dually eligible, as they must have access to private areas where they can speak freely.)

If mailed:

How will copies be distributed?

What will be the timeframe for people to return the surveys?

Will responses be anonymous?

What will be done to make the process of getting the information back to the entity conducting the survey easier for the consumer? Will incentives be included for people to complete and send back the forms?

If conducted by phone or in person, who will conduct the surveys (including training)?

What will be an acceptable response rate; how can the number of returns be increased if an acceptable rate is not reached within the initial time frame?

Examples of how states have dealt with logistical issues on surveys include:

- I Care staff send a mail-in survey with the member newsletter every six months. Consumers are asked to describe their satisfaction level with the program, I Care staff (including care coordinators), and providers. The most recent survey asked

more in-depth questions about provider changes and consumer complaints.

- New Jersey contracted independent research agencies to conduct a telephone survey among the SSI population enrolled in managed care in four counties (two in the northern part of the state, closer to New York City; two in the southern, less densely populated part of the state). Interviews lasted approximately 25 minutes, and included questions on whether the individual was more satisfied with his/her health plan or with fee-for service Medicaid in 12 areas.

Logistical Issues: **Interviews (mostly open-ended questions)**

Will interviews be conducted by phone, in-person, or some other way?

What questions will provide the most useful information?

Approximately how long will the interview take?

Who will conduct the interviews (including credentials and training)?

Examples of how states have dealt with interview logistics include:

- In planning Wisconsin's Partnership Program, interviews were conducted via phone and Internet with physically disabled consumers (including many who were dually eligible). Questions were asked about interactions with their current health care system, concerns about a potential managed care program, and types of care decisions in which they would like to participate.
- Thirty family members, identified by I Care consumers, were interviewed via telephone to learn their satisfaction with the program. The survey — adapted from Tessler and Gamache's *Family Experiences Interview Schedule* (1995) and Tessler and Gamache's *The Family Burden Interview schedule, Short Form* (1996) — asked for their feelings about service availability, responsiveness of the service system to their needs, their ability to make health care choices, and their general level of satisfaction with services.¹⁹

¹⁹ Human Services Research Institute. *Wisconsin Special Care Initiative Project: Evaluation of Independent Care (I Care) - Family Satisfaction Substudy Final Report*, December 17, 1996, page 9.

Logistical Issues: **Focus Groups**

How many groups will be held?

How many people will be involved in each group?

What will the composition of the groups be?

Who will facilitate the discussions (including experience)?

What questions will provide the most useful information?

How will the proceedings be recorded?

Where/when/for how long will the sessions be held?

Examples of how states have dealt with focus group logistics include:

- Once operational, Human Services Research Institute held five focus groups with individuals (including people who were dually eligible) who were eligible for, and had received information on, the I Care. Three groups were held with people who chose to enroll, two with people who chose not to enroll or disenrolled. During the sessions, participants were asked for their reasons for joining/not joining I Care, their health care needs, and whether the marketing materials they received were helpful in making a decision.
- Before designing Minnesota Senior Health Options, state planners held five focus groups which included both dually eligible people and family members. Participants discussed what they would like in an integrated acute and long-term care program, what information they would need to make choices and how to best provide that information.
- In developing a needs assessment required by Wisconsin Partnership officials, Access to Independence, the community-based organization focusing on people with severe disabilities (including many who were dually eligible) in Dane County, held approximately 20 focus groups. The first groups were asked what they felt were necessary pieces of long-term support services and health care for people with disabilities, and about problems experienced with their current health care and long-term support services. Later focus groups, composed of people who obtain services from personal care workers, focused on desired aspects of a personal

care program, including quality indicators, training, back-up services, communication, worker retention, consumer direction and control, and agency involvement.

Logistical Issues: **Meetings/Public Forums**

What will the agenda include?

When/where/for how long will the meeting be held?

Who (from the state agency, contractor, providers) should be involved?

Examples of how states have dealt with meeting/forum logistics include:

- Colorado held two public forums at the site of the proposed Integrated Care and Financing Project. Twelve employees of the State and proposed health plan participated. The Director of the Mesa County Department of Social Services welcomed attendees; the Department of Health Care Policy and Financing's Manager of Delivery System Development provided a brief presentation of the Project and, with other staff, answered questions.
- Wisconsin's Medicaid Managed Care program (serving AFDC/TANF and related populations) holds quarterly forums in each of the state's six regions. Bureau of Health Care Financing Managed Care Section staff coordinate and chair these two-three hour meetings. Regular reports are given regarding the ombudsman program, enrollment contractor and public health departments, in addition to discussions of issues of regional concern. Representatives of State agencies dealing with public health, supportive living, and services for families and children are invited to participate. The forums are targeted to mental health boards, county human and social services, tribal agencies, public health departments and advocacy groups.

Logistical Issues: **Advisory Committees/Workgroups**

Will there be representatives of specific populations/groups or will anyone who would like to participate become a member?

What will be the expectations of individual members (e.g., in addition to attending committee meetings, will individuals be expected to attend public forums or focus groups)?

How often will the committee/workgroup meet?

Where will the committee/workgroup meet?

How will the committee/workgroup be educated?

(*Note:* Some of these issues will be decided by the committee/workgroup itself.)

Examples of how states have dealt with logistical issues for advisory committees/workgroups include:

- The Consumer Advisory Council for the Integrated Care and Financing Project is co-chaired by the State's Department of Social Services and Rocky Mountain HMO (the proposed contractor). Monthly 2-hour meetings take place at Rocky Mountain HMO's site in Mesa County.
- In Texas, a 20-member group is meeting in the Harris County area, where the managed care program which integrates acute and long-term care and includes consumers who are dually eligible has just begun enrolling. Individuals were nominated by the State, which sought to ensure that membership was balanced between interests. Monthly meetings are open to the public, attracting an average of 50-60 people.
- The legislation enacting Florida's Long-Term Care Community Diversion Pilot Project creates a Long-Term Interagency Advisory Council to advise the Department of Elderly Affairs on the Project and other long-term care issues. Four of the 13 members appointed to the Council will be consumers, family members or consumer advocates (appointments have not yet been made). The legislation does not specify whether any of these consumers are to be dually eligible.

Logistical Issues: **Complaints/Grievances**

If a consumer has a problem, what steps will he/she have to take to complain/grieve?

Will there be a particular order for a consumer to follow in seeking resolution or will there be a degree of flexibility?

Will someone else (e.g., an advocate) be allowed to complain/grieve for the consumer?

How will consumers be made aware of the process?

What will the timeframe for decisions be?

Will the state have a toll-free hotline for addressing complaints or require contracted plans to have such hotlines? If so, how will the hotline(s) work?

Will the state have an ombudsman office? If so, how will it work? What will be the responsibilities/authority of the office?

What kind of data will managed care plans be required to submit to the State on complaints/grievances received? How will this process work?

How will the State track complaints in its own grievance system?

Examples of how states have dealt with logistical issues around complaints/grievances include:

- In most of the states studied, enrollees with complaints are most frequently directed to go through the plan's procedures first. In Minnesota, Colorado, and Wisconsin's Partnership, the care coordinator is expected to assist enrollees at the plan level. New Jersey offers to intercede on the individual's behalf if so desired.
- In Florida and Colorado, if the issue is not resolved to the consumer's satisfaction at the plan level, at that time he/she can grieve to the state. In Minnesota, Wisconsin's Partnership, and Wisconsin's I Care, consumer can go directly to the State, as well as to the plan.
- Florida's Statewide Provider and Subscriber Assistance Panel handles complaints/grievances at the state level, in addition to the fair hearing process. The six-member panel — which meets bimonthly — is staffed by personnel from the Department of Insurance and the Agency for Health Care Administration (which oversees the Medicaid program) giving it the authority of these agencies.
- New Jersey has an external appeals mechanism, as well as fair hearings. The

peer-review organization has been reviewing appeals, but the State will issue an RFP to fill this role. Decisions are not binding, but plans must explain their reasons for not complying. The State can sanction plans with patterns of non-compliance.

Step 6: Contact Individuals

Develop the “ask” Before actual contact can happen, planners determine ways to approach potential participants. These methods include: letters or other written materials, advertising copy (for kiosks at centers that dually eligible consumers frequent, radio, TV, or newspapers), and scripts for interviewers/recruiters.

The effective “ask” clearly answers the consumer’s question: “What’s in it for me?” In addition to spelling out how input will be used in developing/fine-tuning the program, available incentives for participation could be described.

Consumers may fear that any negative comments will hurt their ability to get future care. It is important to stress that this will not be the case, and where applicable, stress the confidentiality of their responses. For example, in its many focus groups and interviews evaluating I Care, Human Services Research Institute recruiters emphasized confidentiality in the initial phone calls to potential participants.

Direct contact. State planners may want to work with people “in the know” to identify individuals they hope to involve. Advocates, health plans, providers (including those providing non-medical services), and community agencies can all be resources in identifying individuals who may want to participate.

Asking these groups for assistance in identifying potential consumers/family members need not require them to breach confidentiality. The planner can ask the organization to estimate the number of their contacts who may be interested in participating. The planner can then create a document (e.g., a survey or an announcement advertising an upcoming forum), stuff copies of the document into stamped envelopes for the estimated number of potential participants, and ask the organization to label the envelopes. The organization could also be asked to place copies of the document in prominent places (such as in waiting rooms or on kiosks) or for direct care workers to make copies available to their clients.

- In recruiting potential participants for five focus groups evaluating Wisconsin’s I

Care program, Human Services Research Institute contacted individuals by phone, then followed up with letters confirming participation.

- Seventy-six family members were identified by I Care consumers, who were asked to voluntarily provide a family member's name and phone number for a study on family satisfaction. Of these, thirty family members were surveyed by Human Services Research Institute telephone interviewers (most of the non-completed interviews were due to problems contacting the person named) after receiving a letter describing the process and asking for their participation.

Advertising can take many forms, from very broad (on radio, television, and newspapers) to very specific (at senior centers, rehabilitation agencies, or other places frequented by consumers who are dually eligible). Advertising in consumer-friendly language may be key in ensuring that a wide range of individuals are aware and can choose to participate.

- In determining needs prior to designing Partnership, the University of Wisconsin-Madison School of Nursing (under contract with Wisconsin officials) advertised the opportunity for an interview to various Internet listserv discussion groups.
- For Advocate Advisory Meetings, Wisconsin's I Care staff mail invitations to all interested advocacy groups with multiple dates; groups interested in participating let I Care staff know which dates they can attend. I Care staff call groups that do not respond to encourage them to send a representative.
- Colorado advertised its two public forums on the proposed Integrated Care and Financing Project heavily on radio and television, and sent invitations to people known to be receiving long-term care.

Recruiting for advisory committees/workgroups. Minnesota, Wisconsin's I Care and New Jersey all described difficulties recruiting consumers (and family members available during the day) for advisory committees and workgroups. Ways to combat this problem include:

Working with managed care plans - New Jersey obtained names of potential participants from MCOs. However, Minnesota expressed frustration with its attempts, noting that the plans have had difficulties because of the frailty of many members.

Working with other contacts - New Jersey also obtained names from advocates. Wisconsin's I Care obtained names from care coordinators.

Advertising at public forums - Two programs reported successfully using this method.

- Colorado consumers attending a public forum in July 1996 were invited to participate in a consumer advisory council specifically for the Integrated Care and Financing Project. Of the 19 who initially responded, 12 became members. Between one-half to two-thirds are dually eligible or represent consumers who are.
- In Orange County, California, CalOPTIMA (which enrolls individuals who are dually eligible in CalOPTIMA Direct, a fee-for-service system with prior authorization requirements rather than with capitated subcontractors) held a series of community forums during its development in 1995. Participants in these forums expressed particular concern around six issues — capitation, quality, provider education, family-centered care, access to clinical trials and data collection. Volunteers, including consumers and advocates, formed workgroups around each of these issues.

Step 7: Maximize Meaningful Participation

Overall considerations. In addition to working to minimize potential barriers related to medical fragility, planners who prepare to deal with several issues can facilitate the process of involving clients who are dually eligible:

Working with communication limits - Consumers who are dually eligible may have a variety of conditions which affect their ability to communicate, such as impairments in vision, hearing, or lucidity. Some consumers will have family members, informal care givers, and other representatives who could be included in the process to minimize these barriers. TDD and hearing impaired interpreter services, or materials available in alternative formats may be necessary.

Human Services Research Institute's Cross-Disability Health Outcomes Survey, which included a section on consumer satisfaction, was utilized in interviews with I Care participants. The instrument uses both verbal questions and pictorial representations of questions, developed from a standard picture vocabulary, to obtain information from subjects with varying levels of cognitive and/or emotional limitations.²⁰

²⁰ Human Services Research Institute. *Wisconsin Special Care Initiative Project: Evaluation of Independent Care (I Care) - Consumer Outcomes Substudy Final Report*. December 3, 1997, page 8.

Minimizing “managed-care-speak” - Planners and managers need to be aware of the vocabulary used (e.g., in describing the program in public forums, or spelling out grievance procedures). Wisconsin’s I Care program described difficulties in its initial focus groups due to participants’ lack of understanding jargon.

Surveys. Maximizing the usefulness of surveys involves wording questions so that the answers can guide decision-making, and obtaining responses from as many of the proposed/current consumers (and family members) as possible.

Phrasing the questions - Surveys must be easy to read, understand, and follow. Effective surveys are written at fourth to sixth grade reading levels and have few instructions to remember. Effective mail surveys avoid skip patterns.

Asking respondents to rate levels of satisfaction is of limited use. Research has shown that most people will express satisfaction with any service provided. Also, what one person may find satisfactory another may not. To combat this, surveys are increasingly asking about specific incidences (e.g., “Have you had to wait over 30 minutes in the waiting room to see your primary care doctor?” “Does your doctor explain things to you?”). The best known of these surveys is the CAHPS (Consumer Assessment of Health Plans Study), developed by the U.S. Agency for Health Care Policy and Research (AHCPR). A core set of questions is relevant to all populations; supplemental questions focus on particular populations, such as people with chronic illnesses or disabilities. Survey tools are currently being field-tested; finalization is expected soon. A CAHPS version focusing on Medicare managed care — a mail survey with postcard reminders and telephone follow-up — has already been piloted and is available from the Center for Beneficiary Services at HCFA. However, neither the Medicaid nor Medicare versions of CAHPS ask questions on long-term care, limiting the usefulness of these tools with many populations that are dually eligible.

Maximizing responses - Having mail surveys available in alternative formats will make it easier for dually eligible consumers who have visual impairments to respond. A self-addressed stamped envelope included with the survey form makes it easier for consumers to return it.

Other ways to increase the response rate of mail surveys have been demonstrated by Oregon’s recent survey of SSI beneficiaries in managed care.²¹ Medicaid officials:

²¹ Starr, Janna, Health Policy Specialist, United Cerebral Palsy Association. “What States Need to Know from Health Plans and Consumers” workshop, *Managed Care and Disability: Consumer Needs and Quality Measures* conference, Nov. 18, 1997.

- Sent notices a week prior to sending the survey, emphasizing the importance of completing the survey and stressing that its completion would not affect the person's health benefits in any way.
- Sent a cover letter with the survey, again stressing the importance of the consumer's participation and that no retaliation would result.
- Provided a toll-free hotline for individuals with questions or requesting a survey in a different format or language. Hotline staff were trained to answer basic questions and offer minor assistance in completing the survey.
- Sent a follow-up postcard to everyone one week after the survey (stressing the toll free number for help).
- Sent a follow-up letter to non-respondents in two weeks (again stressing the toll free number).

Note on gauging satisfaction - Some have suggested that as long as satisfaction surveys are distributed by providers to consumers, they will be unlikely to reveal meaningful results.²² For example, several elderly Partnership consumers interviewed by the University of Wisconsin-Madison, School of Nursing indicated that they would be unwilling to fill out a satisfaction survey, especially if they were unsatisfied with the service encounter, but liked their provider.²³ One alternative is to use consumer satisfaction teams, such as those used in parts of Pennsylvania, Ohio, Georgia and Wisconsin. However, recruiting dually eligible consumers or family members to serve on teams would be challenging.

Focus groups Several suggestions may foster participation among all participants:

Small groups - Limit the number of participants in each group. Typically, the maximum for a session is 14 people; if working with individuals with more limited hearing and communication abilities, fewer than 10 would be more workable.

²² Fisher, D. *The Importance of Consumer Involvement in Managed Care Evaluation*. Presentation at HCFA/SAMHSA Waiver Evaluation Project Symposium, Baltimore, April 1996. Quoted in *Quality Assurance Substudy Report*, Human Services Research Institute, page 15.

²³ Bowers. *Building Health Care Systems for People with Chronic Illness....*, page 6.

Homogenous groups - Individuals may be more forthcoming if they participate in focus groups composed solely of consumers or family members; mixing the groups may have a “chilling effect” (especially putting families in the same group).

Alleviating fears - Another possible cause for “chilling effect” is a tape recorder at sessions. To avoid frightening participants, recruiters can mention that one will be used but that the participants’ names will be kept confidential. If participants continue to feel uncomfortable, a person taking notes, instead of the tape recorder, may put them more at ease.

Facilitating - The facilitator may need to be skilled in working with individuals who have communication difficulties. At the start of the session, the facilitator needs to emphasize his/her neutrality; state agency or health plan staff may be less effective at getting people to participate in than facilitators from outside. Advisory committee members could take this role, provided they have group facilitation experience.

Incentives - Offering travel reimbursements, food during the session, and/or incentives such as gift certificates may increase the number of consumers/family members willing to spend one and a half to two hours participating in a session. For example, in evaluating I Care, Human Services Research Institute offered focus group participants \$20 stipends, and arranged for transportation.

Going to the consumers - Minnesota Senior Health Options planners held focus groups (which included both people who are dually eligible and family members) at nursing homes, senior centers, and senior housing facilities.

Public forums Adequate advertising to consumers and advocates may be key to participation. Holding forums in environments familiar to consumers may encourage a more positive meeting. Another key to a more productive gathering is to allow time for public comment, as well as for the State to convey information.

Staff from Minnesota Senior Health Options and Wisconsin’s I Care held forums in public schools, churches, the Social Security Administration, and community organization facilities. Minnesota held over 100 forums during MSHO’s development.

Ongoing meetings, no set membership. The two programs that hold monthly meetings with advocates report that these meetings allow their programs to maintain respect and visibility in the community, as well as to share information and ideas.

- One of Minnesota’s ombudsman staff holds regularly scheduled meetings with advocates. Minnesota Senior Health Options staff also participate.

- Wisconsin's I Care staff conduct monthly Advocate Advisory Meetings in Milwaukee.

Both programs noted that the meetings are used to inform advocates of upcoming program changes, to listen and respond to concerns raised, and to further develop the program through referrals and collaboration. Since MSHO's participants are all dually eligible, as are a high percentage of I Care consumers, issues relevant to these populations are highlighted.

Accessibility - I Care holds meetings at different times and in different locations in order to increase the opportunities for people to participate.

Continuity of participants/education - Despite the lack of set membership, both programs reported that the same advocacy groups send representatives on a regular basis, so educating attendees has not been an ongoing need. One way to help newcomers get "up to speed" would be to create fact sheets that attendees could pick up as they enter.

Advisory committees/workgroups Ways to maximize participation include:

Accessibility - In moving its SSI population to mandatory enrollment, New Jersey began the Workgroup on Managed Care for People with Disabilities nearly three years ago. Meetings have been held in different locations on an as-needed schedule (sometimes as frequently as once per week, but usually once per month). Over 50 individuals have participated.

Education - A key first step in ensuring the success of these groups is to educate members regarding the complexities of Medicaid, Medicare, and managed care. New Jersey's Workgroup on Managed Care for People with Disabilities spent its first six to eight months listening to experts on managed care for SSI populations from around the country, and reading a "truckload" of printed materials. Colorado's Consumer Advisory Council for the Integrated Care and Financing Project started with a series of bi-weekly educational meetings.

Education includes discussions on realistic expectations for the proposed program. New Jersey officials stressed the importance — and the difficulty — of "keeping everyone in the world of the real". Staff emphasize to advocates that managed care may ameliorate some of the problems their consumers face (such as fragmentation of services) but it will not solve all of Medicaid's ills. Staff stress to managed care plans that they must be creative to work effectively with populations new to them.

Role of the committee/workgroup - States generally have groups focus on specific aspects of the proposed program/contract:

- The task of New Jersey's Workgroup on Managed Care for People with Disabilities is to thoroughly review the currently utilized HMO contract and recommend language that will ensure the appropriate provision of services to people with special needs.
- Wisconsin's I Care currently has one consumer involved on each of its 7-member Grievance and Quality Improvement Workgroups. The Quality Improvement Workgroup recently looked at consumer reaction to a reduction of transportation providers, and at satisfaction with transportation services. The Grievance Workgroup reviews all grievances brought to the program.
- For its primary and acute managed care program, Colorado created the Disability Working Group. Composed of an equal number of high-ranking health plan staff and community representatives with physical disabilities (including five individuals who are dually eligible consumers or family members), the Working Group has provided input on proposed contracts. It is facilitated by an independent consultant who has physical disabilities (one of the criteria required by the disability community to come to the table).
- Colorado has two groups involved in the Integrated Care and Financing Project:
 - The Integrated Care and Financing Project Advisory Committee, meeting quarterly in Denver for the past 3 years, has proposed authorizing legislation on rules (including definitions, services provided, licensing, notification and appeals, enrollment and disenrollment procedures, direct payments to clients, administration, rate setting, care coordination team, and quality assurance). Once the Project is operational (Spring 1998), the Committee will examine how it can be replicated in other parts of the state.
 - The Consumer Advisory Council in Mesa County focuses more on more local issues. After the Project begins enrolling, the Council will act as a conduit of information between the State and consumers/family members on how well the Project is working and on areas that need improving.

Colorado officials described initial confusion about the Consumer Advisory Council's role and authority. Some members were unclear as to the distinction between providing recommendations and governing the program. Clarifying this distinction and detailing the "job description" of individual members during recruitment would avoid confusion and possible disillusionment later.

Role of State officials - In many programs (including those in Minnesota, Colorado, Wisconsin and Florida) staff report back during the course of each meeting on issues raised at prior meetings. Other examples of State roles:

- *Chair* - Colorado's Consumer Advisory Council (for the Integrated Care and Financing Project) is co-chaired by the State's Department of Social Services and Rocky Mountain HMO (the proposed contractor).
- *Initiator* - In New Jersey, early meeting agendas were driven by the State. Now, State officials report that the Workgroup identifies the areas it wishes to discuss.
- *Peacemaker* - In Massachusetts, "the presence and influence of state agency committee members was key to breaking through the impasse"²⁴ of lack of trust between parents and advocates on the Medicaid Family Committee and the behavioral managed care plan contracted to provide services for Medicaid populations.

Keeping members involved - Perhaps the most important ways to keep participants engaged are good feedback and clear results. Colorado officials focused on giving Consumer Advisory Council members concrete tasks in which they could see their input used, such as reviewing draft marketing materials. Colorado officials also stressed the importance of responding to questions from Council members as quickly as possible (usually by the next meeting).

Another major factor for consumers' continued interest is the feeling that their input is valued. States tangibly demonstrating their appreciation can facilitate continued participation.

- In New Jersey and Wisconsin's I Care, consumers are reimbursed for transportation and lunch, and offered a minimal stipend.
- Ucare, a Medicaid-only plan in Minnesota, pays a stipend and expenses for consumer members of their Board of Directors to attend meetings. When there are extra meetings or particularly long sessions, the plan also offers gift certificates.

Complaints/grievances Many consumers do not come forward with complaints/grievances, due to lack of knowledge that they can complain, lack of understanding

²⁴ Gross, June. *Families and Policy, a Natural Fit*. Boston, Massachusetts: Parent Professional Advocacy League, Jan. 1998, page 2.

about the process, fear of retaliation from care providers, or sense that complaining is futile. Instead of pursuing grievance procedures, consumers tend to switch doctors or plans, or disenroll.

Increasing awareness - At a recent National Academy for State Health Policy conference, consumers stressed the need to make explanations of grievance procedures simpler,²⁵ in part by having the explanatory materials written at a fourth grade reading level (as an audience member pointed out, “What fourth grader understands the term “grievance procedure”?”).

- Some states have documents explaining the plan’s/state’s grievance process to consumers first reviewed by advisory committees, focus groups, or other consumers.
- In California, contracted plans must have a person available at each service site, as well as at other locations designated by the contractor, to provide assistance in filing grievances and complaints.²⁶

Alleviating fear - The University of Wisconsin-Madison School of Nursing evaluation of Partnership found, “Often the [elderly] consumer was unhappy with, fearful of, or confused by the service or provider but was reluctant to say so. Unwillingness to express negative sentiments was explained by: fear of retaliation, fear of displeasing providers, fear of being perceived as uncooperative or unappreciative, fear of losing service altogether, or fear that the replacement will be worse.”²⁷ Having people believe that their complaints are welcome and valid requires a great deal of education.

Two frequently used mechanisms for making the complaint/grievance process more user-friendly are toll-free hotlines and ombudsman programs.

Toll-free hotlines, available in most Medicaid managed care programs, may be run by the State, county, plan, enrollment broker, or outside entity. Many complaints can be resolved by providing consumers accurate information about how the health care delivery system works. Hotline staff can quickly and easily help these consumers.

²⁵ “What Consumers Want: Meeting Consumers’ Needs”, *Behavioral Health in Medicaid Managed Care: A “How To” for State Policymakers*. National Academy for State Health Policy, August 12, 1997.

²⁶ Perkins, et al, page 58.

²⁷ Bowers. *Building Health Care Systems for People with Chronic Illness....*, page 24.

Consumer awareness is key to a hotline's success. Once consumers are aware, adequate staffing increases consumer satisfaction with the hotline itself and encourages future usage. It is important that hotline staff — including bilingual staff — are adequately trained to provide accurate responses to questions raised by dually eligible callers, and to link callers with questions they cannot answer to staff who can.

Making accommodations for consumers who use TDD or other adaptive communication technology may help dually eligible consumers who have hearing or other communication impairments. Another limitation for consumers who are dually eligible: if residing in nursing facilities, consumers may be unable to access phones in areas where they do not have to worry about conversations being overheard.

- Colorado's Office of Consumer Education and Affairs staffs a hotline with trained advocates. All calls are tracked. A hotline has also been set up in Mesa County for individuals looking for information on the Integrated Care and Financing Project.
- Tennessee contracts hotline services to a consumer coalition and an advocacy center, in addition to its internally-run member services hotline. Every call is tracked. A follow-up call is made to each caller three to four weeks after his/her case is closed. The TennCare Consumer Advocacy Program, a service of the Tennessee Health Care Campaign and the Crisis Intervention Center, aggressively conducts outreach efforts to inform clients about how to use the hotline service.²⁸

Ombudsman programs are generally considered helpful to enrollees. Most problems are resolved informally. These programs also serve as good education sources for consumers. Also important to planners, tracking through a single office allows problems which may affect many enrollees to be identified quickly.

- Minnesota's ombudsman program operates directly out of the Medicaid office, with the full weight and authority of that agency in mediating disputes and obtaining resolution from MCOs.²⁹ There is a direct link between the program and the Medicaid managed care quality improvement office. One ombudsman staff person focuses on aging issues, another on long-term care. Enrollees can access the program without first going through a plan's grievance procedures.

²⁸ Perkins, et al, page 52.

²⁹ Horvath and Kaye. *Snapshot....*, page 10.

- Oregon's ombudsman program specifically serves the elderly and SSI Medicaid populations (including many dually eligible consumers). Like Minnesota's, the program operates from the Medicaid office, and has the full authority of this office. Consumers are given the ombudsman program's toll free phone number with their monthly notice of Medicaid eligibility.
- Florida staff will train Area Agencies on Aging (AAAs) to serve as advocates in the Long-Term Care Community Diversion Pilot Project areas. AAA staff will be trained on State and plan grievance procedures so that they can assist enrollees throughout the process.
- Florida is piloting an ombudsman program for all consumers in managed care, regardless of whether in Medicaid, Medicare or commercial plan. Volunteer teams will investigate complaints and help consumers with grievances, with the authority of the Medicaid agency. The nine to sixteen member teams will be composed of medical and other professionals and at least one consumer.
- Wisconsin's ombudsman program is run by the Medicaid fiscal agent (EDS) and has working relationships with the Bureau of Health Care Financing's Managed Care Section, the enrollment contractor (which is to refer consumers with complaints), the HMO advocate and community advocacy groups.³⁰

Involving consumers in the grievance process - Several states involve consumers in grievance gathering and/or decision-making:

- Massachusetts Behavioral Health Partnership, the sole contractor for managed behavioral health services for Medicaid populations, allows consumers and family members to go directly with complaints to the Medicaid Family Committee, which funnels the complaints to the appropriate persons.
- I Care's Grievance Workgroup, which currently has one consumer involved, meets on an as-needed basis to review all grievances brought to the program. Currently reaching this level of review are durable medical equipment denials. (Other complaints and grievances are resolved before reaching this level.)

³⁰ Wisconsin Department of Health, Bureau of Health Care Financing. *Medicaid Managed Care Statewide Advocacy Program*. January 31, 1997, page 3.

Step 8: Provide Feedback

It is important that consumers are aware that their input is being considered and have an impact, even if their suggestions are not ultimately used.

- Colorado officials described instances in which they did not follow a particular consumer or advocate recommendation and were characterized as ignoring consumer input. State officials found that taking the time to explain in detail (sometimes both verbally and in writing) why they chose not to follow the particular recommendation ameliorated this problem.
- New Jersey stressed the importance of listening to consumers' fears and realistically responding to them.

Reporting back to ongoing groups - In many programs with advisory committees, workgroups, or other regularly meeting groups (including those in Minnesota, Colorado, Wisconsin and Florida), State staff report back during the course of each meeting on issues raised at prior meetings.

Making satisfaction data public - On nonclinical issues (such as interactions with providers), consumers trust the opinions of other consumers more than any other source. Consumer satisfaction results can be packaged to help potential enrollees make choices. Moreover, making satisfaction information public can be an important element in a State's strategy to keep plans accountable. If planners wish to make satisfaction information public, they need to keep in mind that satisfaction surveys designed and implemented by different plans may not be comparable, so they may want to conduct such surveys themselves.

- New Jersey makes the results of consumer satisfaction surveys available on publicly accessible computers in welfare and county offices throughout the state, as well as mailing to anyone requesting them.
- Minnesota's annual report cards include consumer satisfaction data.
- Data from Oregon's ombudsman program is available to the public.

Consumers who are dually eligible and need long-term care services will want to see items measured which are not generally included in versions of consumer satisfaction results packaged for larger populations.

Using Consumer Input: Examples

Program Structure

- Proposed mandatory enrollment for Wisconsin's I Care program became voluntary as a result of advocate and consumer concerns expressed in meetings and focus groups.
- I Care's initially proposed specialty clinic model was changed to a provider network design, due to consumer concerns about stigmatization and disruption of existing provider care.
- CalOPTIMA (Orange County, California)'s Capitation Workgroup — which included both consumers and advocates — focused on determining an AIDS-specific capitation rate. Working with an actuarial consultant, the Workgroup determined a rate during six meetings.

RFPs/RFAs, Contracts

- In Wisconsin, a survey conducted in late 1991/early 1992 to start planning I Care indicated that provider choice and continuity of relationships with current providers were key concerns. This resulted in the following criteria being used to evaluate proposed provider networks.
 - Geographic distribution
 - Current affiliation with SSI/disabled population
 - Indication by cost data as a frequently utilized provider
 - Proven sensitivity to the special needs of the population
 - Cultural competency.
- In New Jersey, issues expressed in the satisfaction surveys about appointment waiting times and referral processes resulted in more detailed and tighter RFP standards. Also included in the new RFP are the recommendations of the Workgroup on Managed Care for People with Disabilities on systems (including finance), quality assurance, capitated benefits, and education and outreach.

Other Written Materials

- In Wisconsin, consumer groups reviewing I Care marketing materials had issues important to Consumers — assistance with transportation, elimination of copayments, care coordination, and home and social service coordination — highlighted in the materials.
- Massachusetts (which does not currently enroll dually eligible consumers) revamped its member enrollment materials to incorporate consumer and advocate feedback. Prior to this revamping, only 30% of beneficiaries chose a plan; with the consumer-directed changes, 70% chose a plan.³¹
- The San Francisco Department of Public Health’s community advisory committee developed the text of the orientation booklet provided to all new plan members.
- The Medicaid Family Committee of Massachusetts’ contractor for managed behavioral health services for Medicaid populations created a resource document for providers, advocates, and family members, which included available resources and whom to call on plan-related issues.

Quality Issues

- In Wisconsin’s I Care program, a review of home health care services — precipitated by a grievance — revealed significant deficiencies in the way services were being provided. An effort followed to tighten loopholes and create safeguards that related to quality in home health care service provision.³²
- Colorado’s Integrated Care and Financing Project Consumer Advisory Council’s comments on contract stipulations for plan internal quality assurance are currently being incorporated into the draft.
- Colorado changed the Integrated Care and Financing Project’s complaints/grievance process as a result of the Council’s input. Program rules were changed to include a provision for clients to meet with the care coordination team to complain/grieve.

³¹ Interview with Dr. Annette Hanson, Medical Director, Massachusetts Division of Medical Assistance, July 25, 1997.

³² Human Services Research Institute, *...I Care - Quality Assurance Substudy Final Report*, page 19.

- Protocols for Wisconsin's Partnership's Model Quality Improvement reviews, used by contractors to build and refine quality improvement efforts, were developed through in-depth interviews with consumers and providers, examining how they operationalize quality care.
- In Massachusetts, the behavioral managed care plan serving Medicaid populations convened a stakeholder group, including consumers and family members, to develop performance standards. Standards were developed for components of care, aftercare planning, family involvement, continuing care, care level definitions and requirements, service linkage, staffing, assessments, treatment protocols, quality improvement, disposition planning, and performance/outcome measures.³³
- Tennessee has advocates meet with managed care organizations during State-organized trainings to describe the problems they hear from TennCare consumers.

Other Areas

- One of Partnership's contractors conducted a survey among consumers and family members regarding misplaced articles (some dually eligible people have cognitive impairments which cause them to easily misplace articles or pick up articles belonging to others). The results of the survey were used to train care coordinators and family members in ways to arrange articles so that consumers would be less likely to misplace them.
- Community Care for the Elderly, Partnership's Milwaukee County contractor, developed a spirituality committee as a result of consumer requests made to care coordination teams. Consumers participate on this committee.
- Community Medical Alliance, a Massachusetts health plan serving Medicaid-eligible people with severe disabilities (including dually eligible people), responded to many requests from its enrollees for nonemergency transportation. Nonemergency transportation is not covered by the plan, as Massachusetts' Department of Medical Assistance (DMA) pays for it fee-for-service. Surveying enrollees on the reasons for these requests unveiled several problems accessing the DMA transportation coverage, including a 3-day reservation requirement and a 1-month lag between

³³ Gross, page 3.

Medicaid enrollment and accessing transportation. This information was forwarded to the DMA office, which is now facilitating meetings with the transportation vendor.³⁴

Conclusion

States which have made a commitment to consumer involvement report that it has significantly helped their programs, plus they have developed relationships that help resolve issues when problems arise. For example, the Human Services Research Institute evaluation of Wisconsin's I Care program noted, "Consumer, family and advocates' involvement with the design and monitoring of I Care has helped achieve respect in the community for I Care that may not have otherwise been there."³⁵

Consumer involvement plays an important role in consumer satisfaction, which may be especially significant in keeping dually eligible people voluntarily enrolled in the program.

How to Maximize Meaningful Involvement: Lessons Learned

- ✓ Getting consumers involved requires energy and dedication to ensure that input is gathered from a variety of consumers and family members on an ongoing basis, is used as appropriate, and is "fed back" to show how it has been used.
- ✓ Get the input of people who have chosen not to enroll or have disenrolled, as well as current enrollees, in order to get a fuller picture of services desired and marketing/educational issues.

³⁴ Wagner, Laura, Chief Operating Officer, Community Medical Alliance, "Quality Improvement in Action - Health Plan Initiatives" plenary, *Managed Care and Disability: Consumer Needs and Quality Measures* conference.

³⁵ Human Services Research Institute, *Wisconsin Special Initiative Project: Evaluation of Independent Care (I Care) - Getting Started: Implementation Substudy Final Report*, October 10, 1996, page 30.

- ✓ Be sensitive to the vocabulary used in describing the program in public forums, spelling out grievance procedures, or other interfacing with consumers.
- ✓ Work with people “in the know” (such as advocates, health plans, and providers) to identify individuals you hope to involve.
- ✓ Stress that consumers participating need not fear retaliation.
- ✓ Advertise upcoming opportunities for participation broadly (e.g., on radio and television), as well as to members of the targeted group (e.g., sending invitations to dually eligible people known to be receiving long-term care).
- ✓ Use input mechanisms (such as public forums) to advertise upcoming opportunities for involvement. However, be wary of overusing a small number of consumers because they express interest and make themselves available.
- ✓ Use the Internet (including listserv groups) to advertise upcoming meetings, survey potential/current consumers, and otherwise communicate (although none of the states mentioned it, an ombudsman e-mail address may also be helpful).
- ✓ To increase the accessibility of meetings, hold them in different locations, at different times (especially in the evenings), or via teleconference. However, make sure that the meetings are advertised, or the changes in locations/times may cause confusion and keep newcomers away.
- ✓ Public forums — held in such places as public schools, churches, the Social Security Administration, and community organization facilities — are effective ways to reach a wide variety of potential consumers/family members both for education and to obtain comment. Hold these forums in places that dually eligible consumers use.
- ✓ Use tangible ways (such as transportation reimbursements, food at meetings, small stipends, or gift certificates) to demonstrate that you value consumer input when this participation requires a significant time commitment.
- ✓ Identify issues on which to conduct satisfaction surveys with the help of those in daily contact with dually eligible consumers, such as care coordination teams.
- ✓ Asking respondents questions about specific incidences is more useful than asking them to rate satisfaction.
- ✓ Ways to increase the response rate of mail surveys include: sending out notices prior to sending the survey reassuring consumers that participating will not affect their benefits, providing a toll-free hotline for questions, sending a follow-up postcard to everyone one week after the survey is sent, and sending a follow-up letter to non-respondents in two weeks.

- ✓ To foster participation among focus group participants: limit the number of participants, keep groups homogenous, be sensitive to things that may cause the “chilling effect” (such as tape recording the session or having the group facilitated by a State or health plan representative), use a facilitator skilled in working with individuals who have communication difficulties, offer incentives, and hold sessions at facilities frequented by consumers who are dually eligible.

- ✓ Educate advisory committee/workgroup members on the complexities of Medicaid, Medicare, and managed care. Include discussions on realistic expectations for the proposed program.
- ✓ Report back during the course of each advisory committee/workgroup/regularly scheduled meeting on issues raised at the prior meeting.
- ✓ Implement methods that help take the fear and confusion out of complaining/grieving, such as toll-free hotlines and ombudsman programs. Advertise these services. Make accommodations for consumers who use TDD or other adaptive communication technology to help some people who are dually eligible.
- ✓ Have draft documents explaining the plan's/state's grievance processes reviewed by advisory committees to ensure that consumers will find them useful.
- ✓ Take the time to explain in detail (sometimes both verbally and in writing) why you chose not to follow a particular consumer/advocate recommendation in order to avoid being characterized as ignoring consumer input.
- ✓ Making satisfaction data public will let consumers know that their input is valued and can be an important element in the State's strategy to keep plans accountable.

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Appendices

Appendix A

Dual Eligibility

Definition¹ People who are **dually eligible** are aged, blind or disabled, and eligible for both Medicaid and Medicare by falling into either Medicare eligibility group *and* any Medicaid eligibility group listed below:

Medicare Eligibility Groups

Most people *age 65 or older*.

People under age 65 receiving Social Security benefits on the basis of *disability*, following a two-year waiting period.

Major Medicaid Eligibility Groups

People receiving *full Medicaid benefits*, either because they are eligible for SSI benefits, or because the state has exercised one of several options to extend benefits to people not receiving SSI. Eligibility categories include:

- *SSI* - People who are aged, blind or disabled, and meet income and resource tests.
- *SSI Related (optional)* - People meeting SSI eligibility requirements, including resource tests, except that their incomes fall between the SSI standard and 100% of the federal poverty level.
- *Qualified Medicare Beneficiary (QMB) Full Benefits (optional)* - People who are aged, blind or disabled, receive Medicare Part A, and meet income and resource tests. Federal law requires the State to pay for Medicare premiums, deductibles and coinsurance, and gives the State the option to provide for full Medicaid benefits.
- *300% Rule (optional)* - People meeting the medical/functional nursing facility criteria and having incomes no greater than 300% of the SSI benefit payable to a person living at home with no income.

At the State's option, people receiving *Medicaid benefits, which may be less than full Medicaid benefits*. Eligibility categories include:

- *Medically Needy, No Spend Down* - People who would be categorically eligible but for income and assets. The State may set the income standard up to 133.33% of the TANF payment level for a similar family/household.
- *Medically Needy with Spend Down* - Same as above, except the State allows additional income (beyond 133.33%) to be offset against medical expenses.

¹ Information taken from: Saucier, Paul. *Federal Barriers to Managed Care for Dually Eligible Persons*. Portland, Maine: National Academy for State Health Policy, August 1995, Appendix.

People for whom Medicaid pays *Medicare cost-sharing expenses only*. Eligibility categories include:

- *Qualified Medicare Beneficiary (QMB) Cost-Sharing Only* - People who are aged, blind or disabled and receiving Medicare Part A, but do not meet the income or resource tests for categorical eligibility (having incomes up to 100% of the federal poverty level and assets of up to 200% of the allowable SSI amount). Federal law requires the State to pay for Medicare premiums, deductibles and coinsurance, and gives the State the option to pay for HMO premiums.
- *Specified Low-Income Medicare Beneficiaries (SLIMB)* - People meeting QMB criteria except their incomes fall between 100% and 120% of the federal poverty level. The State pays Medicare Part B premiums only.
- *Qualified Disabled and Working Individuals (QDWI)* - People who have lost their former eligibility for Social Security Disability and Medicare, but are exercising the option of keeping Medicare by paying the Part A premium. The State must pay the Part A premium if these individuals' incomes are less than 200% of poverty, and assets are less than twice the SSI standard.

Populations It is estimated that:

- Approximately 3.7 million elderly persons are dually eligible (nearly all elderly Medicaid beneficiaries; nearly 12% of elderly Medicare beneficiaries)²
- Approximately 1.5 million persons below age 65 who have disabilities are dually eligible³ (about one-third of Medicaid beneficiaries with disabilities⁴).

Rather than a homogenous group, individuals who are dually eligible have different incomes and medical needs, of which planners need to be aware. For example, a Medicare eligible person who has become eligible for Medicaid through a “spend-down” option may have greater care needs than an elderly person who is categorically eligible for Medicaid through SSI; the “spend down” person has become eligible due to high medical expenses, while the categorically eligible person is only known to be aged and poor (the only requirements of SSI eligibility).⁵

² Saucier, Paul, *Federal Barriers to Managed Care for Dually Eligible Persons*. Portland, Maine: National Academy for State Health Policy, August 1995, Appendix.

³ Ibid.

⁴ Saucier, Paul and Mitchell, J. Elizabeth. “What Is Dual Eligibility?”, *Spotlight*. The Center for Vulnerable Populations/National Academy for State Health Policy, Volume 3, No. 1, November 1995, page 1.

⁵ Saucier, Appendix.

Despite the distinctions, however, many people who are dually eligible have greater health care needs than Medicaid- or Medicare-only beneficiaries.

Greater Health Care Needs of People Who Are Dually Eligible⁶

Cognitive or mental impairments are more likely to be found in people who are dually eligible (22%) than Medicare-only beneficiaries (5%).

More people who are dually eligible live in institutions (24%) than Medicare-only beneficiaries (2%).

Thirty-four percent of people who are dually eligible have an impairment in one activity of daily living compared to 10% of Medicare-only beneficiaries.

Eighteen percent have four or more activities of daily living impairments compared to 3% for Medicare-only beneficiaries.

⁶ All figures taken from *A Profile of Dually Eligible Beneficiaries*, Health Care Financing Administration, March 1997.

Appendix B

Comparison of Five States' Consumer Involvement Mechanisms

	Colorado	Florida	Minnesota	New Jersey	Wisconsin (I Care, Partner.)	
	<p><i>Integrated Care and Financing Project.</i> will combine Medicare & Medicaid health, social & supportive services through a multi-disciplinary team.</p>	<p><i>Long-Term Care Community Diversion Pilot Project.</i> will provide acute care, home & community-based long-term care, & when necessary, NF care through MCOs. (Program set up as an alternative to institutional care.)</p>	<p><i>Minnesota Senior Health Options (MSHO):</i> coordinates all Medicare & Medicaid services through a single contract w/ managed care plans. MSHO also has single enrollment, grievance & quality assurance procedures.</p>	<p>Includes dual eligibles in its <i>Medicaid managed care program.</i></p>	<p><i>Independent Care (I Care):</i> coordinates primary, acute & social services for people over age 15 w/ disabilities through care coordinators in managed care. (Medicare services are not capitated.)</p>	<p><i>Partnership:</i> coordinates primary, acute and long-term care services for NF-eligible persons age 55 and older in Milwaukee & Dane Counties, people aged 18-64 with severe disabilities in Dane County, and both populations in 2 rural counties.</p>
General Program Characteristics						
<i>Waivers</i>	1115	1115	1115	1915(b)	No waiver	Currently operates under PACE 1115; expects its own 1115 soon
<i>Area(s) Covered</i>	Mesa County	Palm Beach area (4 cities) & Orange County (4 cities)	7 counties around metropolitan Minneapolis/St. Paul	Where risk-based plans are available	Milwaukee County	Milwaukee & Dane Counties, & 2 rural counties

	Colorado	Florida	Minnesota	New Jersey	Wisconsin (I Care, Partner.)	
Status of Enrollment	Not yet enrolling (planned start: spring 1998)	Not yet enrolling	Began enrolling January 1997	Plan to phase in mandatory enrollment for SSI in summer 1999 (although will continue to be voluntary for duals)	Began enrolling July 1994	Began enrolling February 1996
Eligibility (Note: all six programs are voluntary)	Medicaid beneficiaries (primarily elderly, so most will be dually eligible)	Dual eligibles over age 65 who meet Medicaid financial eligibility requirements up to the Institutional Care Program level & who are either at risk of NF placement or meet clinical eligibility criteria	Elderly Medicaid beneficiaries. Exceptions: Qualified Medicaid Beneficiaries (QMBs) eligible for cost-sharing only	All Medicaid categorically eligible. Exceptions: Persons in NFs, with developmental disabilities living in institutions, or enrolled in other waiver programs	Medicaid beneficiaries over age 15 with disabilities. Exceptions: Persons in enrolled in other waiver programs	Mil. Cty. - Medicaid beneficiaries over age 55. Dane Cty. - Medicaid beneficiaries aged 18-64. Two rural counties - both populations. All programs - majority of enrollees are dually eligible
Benefit Package	Primary, acute, and long-term care, including social & supportive services, through NFs & HCB	Primary, acute, & long-term care (except NF)	Medicare & Medicaid acute, primary, & long-term care including HCB services. 180-day limit for NF	Primary & acute (if eligible for long-term care, person is disenrolled & returned to fee-for-service.)	Primary, acute, social support, & certain community-based chronic care. 90-day limit for NF	Primary, acute, long-term care
Includes care coordination for all participants	Yes	Yes	Yes		Yes	Yes

	Colorado	Florida	Minnesota	New Jersey	Wisconsin (I Care, Partner.)	
Contractors	Commercial HMO	Licensed HMO w/ contract to deliver capitated Medicare services in pilot area, experience delivering HCB services, & meets requirements to enroll as a Medicaid prepaid health services provider (contractor to be determined)	Commercial HMOs, Medicaid-only HMOs, county plans. Enrollees must receive both Medicare & Medicaid services from the contractor	State licensed HMOs	Commercial HMO in affiliation w/ rehabilitation agency	Community-based organizations
Consumer Input in Program Design/Development						
Surveys				Consumers	Consumers	Consumers, family members surveyed by plans; U. of Wisc. study on long-term care needs
Regularly scheduled meetings			Advocates meet w/ ombudsman staff; state attend monthly meetings of county advocates	Consumers & advocates	Advocates (meet monthly)	
Public hearings/ forums	Yes - formal	Yes	100+ (both formal & informal)	Both during development & operation; held regionally (both formal & informal)	Both formal & informal	

	Colorado	Florida	Minnesota	New Jersey	Wisconsin (I Care, Partner.)	
Advisory committees/ work groups	Statewide task force (inc. consumers & advocates) meets quarterly. Local consumer advisory council meets monthly. State requires MCOs to have active consumer advisory committees	Advisory committee (inc. consumers & advocates) being developed for Project	Includes advocates. (Still working on identifying consumers or family members to invite.) Committee meets monthly	Statewide task force (inc. consumers & advocates) meets twice/yr to advise state. In the process of moving SSI to mandatory, workgroup (inc. consumers & advocates) developed recommendations for RFP. State requires MCOs to have active consumer advisory committees	Consumers & advocates involved in grievance, quality improvement workgroups	No, but contractors required to have advisory committees, as well as workgroups on marketing, grievances and ethics; all are to include dually eligible consumers
Focus groups			Held 5 groups during development w/ dual eligibles & family members		Held 5 groups during development w/ dual eligibles & family members. Continue to hold groups periodically	Held groups during development with consumers, (mostly dual eligible). Plans hold groups periodically
Written comments on drafts	Consumer advisory committee	Advocates (especially Area Agencies on Aging)		Advocates	Consumers & advocates	Consumers & advocates

	Colorado	Florida	Minnesota	New Jersey	Wisconsin (I Care, Partner.)	
<i>Consumer Involvement in Program Operation at the State & Plan Levels</i>						
<i>Independent entity conducts consumer satisfaction surveys</i>				Yes	Yes (both among consumers & family members)	
<i>State conducts enrollee satisfaction surveys</i>	Once project is operational, will conduct satisfaction surveys		Currently being developed			Yes. Also, currently conducting a survey on why eligible beneficiaries choose/decline to enroll
<i>State requires plan to conduct enrollee satisfaction surveys</i>	Yes (according to proposed contract)	Yes (according to proposed requirements)	Yes	Yes	Yes	Yes
<i>Tracking complaints/grievances</i>	Once project is operational, will track	Once project is operational, will track	Yes	Yes	Yes (reported monthly to I Care Board, quarterly to state)	Yes
<i>Tracking voluntary disenrollment/ plan switching</i>	Yes, according to proposed system	Yes, according to proposed system	Yes	Yes	Yes	Yes

	Colorado	Florida	Minnesota	New Jersey	Wisconsin (I Care, Partner.)	
Disenrollment surveys			Yes	Yes	No, but input gained through focus groups w/ disenrollees	Will be part of enrollment survey (see above)
Toll-free hotlines	Yes	Include aged in & out of NFs in general managed care hotline	At state, MCO & county level - Include aged in & out of NFs	Include aged out of NFs	Set up specifically for aged in & out of NFs	Plans required to have own hotlines
Ombudsman programs	Once project is operational, will create program	Area Agencies on Aging staff being trained to assist enrollees through both plan & state grievance procedures	At state level - Has authority of Medicaid agency. Includes staff focused on aging, long-term care issues. (Also have advocates at county level who work closely w/ state ombudsman)		Contractor has both advocate and ombudsman programs serving I Care members	

HCB = Home & Community Based (Services)

NF = Nursing Facility

N/A = Not applicable