



Rutgers Center for
State Health Policy

The Institute for Health, Health Care Policy, and Aging Research

**Transitions Into
New Jersey Family Care 2000+
Experiences of Consumers with Developmental
Disabilities and Their Families**

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Transitions in New Jersey Care 2000+ ERRATA SHEET

Figure 22 on page 19 should appear as follows:

Figure 30 on page 21 should appear as follows:

Figure 22. Respondents reporting difficulties when calling an HBC (N=159)

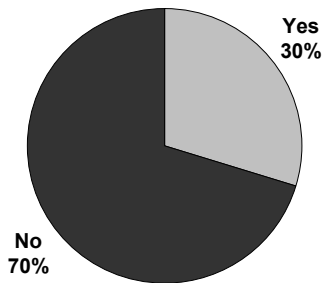


Figure 30. Reports of problems receiving ID cards (N=325)

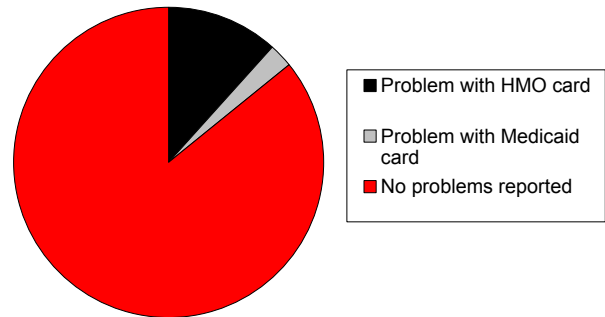
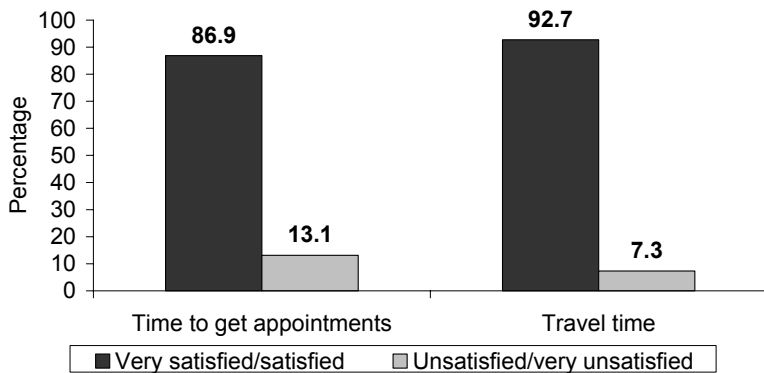


Figure 44 on page 27 should appear as follows:

Figure 44: Rating of satisfaction with convenience of specialists (N=222)



Acknowledgements

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Transitions into New Jersey Care 2000+

Experiences of Consumers with Developmental Disabilities and their Families

Dorothy Gaboda, M.S.W., Ph.D.; Thomas Trail, M.S.; Igda Martinez, B.A.; Susan Brownlee, Ph.D.

Executive Summary

In October 2000, the New Jersey Department of Human Services, Division of Medical Assistance and Health Services, implemented New Jersey Care 2000+ to provide managed care for Supplemental Security Income Aged, Blind and Permanently Disabled beneficiaries, a group which includes many individuals with developmental disabilities.

The New Jersey Council on Developmental Disabilities commissioned the Center for State Health Policy at Rutgers University to conduct a study to document the experiences of individuals with developmental disabilities during their transition from fee-for-service into managed care and identify issues which present barriers to successfully receiving services. Individuals served by the Division of Developmental Disabilities (DDD) were selected for the study because all medical care, as well as mental health and substance abuse services, are provided to these individuals through managed care rather than fee-for-service. Between September 2002 and July 2003, researchers at the Center for State Health Policy conducted a two part study: a survey of 325 randomly selected individuals who enrolled in New Jersey Care 2000+ between October 2000 and September 2002, followed by in-depth semi-structured interviews with 37 of the people who completed the survey. The interviews were designed to focus in depth on understanding any difficulties which individuals had experienced enrolling and receiving services from their health maintenance

organization (HMO), and their problem-solving strategies for dealing with them.

The survey found that 63% of respondents had no difficulty enrolling in the program and choosing an HMO. Most people indicated that they chose their health plan because they could keep their previous primary doctors and specialists. Almost half (48.9%) of individuals received information and assistance from Health Benefits Coordinators, and respondents reported that they got help selecting their HMO from a family member/guardian (44.1%) or a nurse, doctor, or social worker (17.8%). The primary source of difficulty during enrollment that people reported was obtaining up-to-date information about which doctors participated in the various HMO networks.

Overall, 63% of survey respondents indicated that they were satisfied with their HMO, although satisfaction varied by health plan. About half called their HMO with questions, and, of those that called, a third reported waiting more than 5 minutes to speak with someone. Issues discussed in the calls included reimbursement for brand name medications, referrals

to specialists, and inquiries about new services.

Half of respondents had been linked with a care manager (a person employed by an HMO to help coordinate services), and satisfaction with care management was very high. Care managers provided substantial assistance with referrals and provision of new services. When asked what the best part of being in their HMO was, many respondents mentioned their care manager's help in solving problems. However, some participants expressed concern about turnover among care managers, which interfered with continuity of care, while others had not been able to obtain a care manager.

The survey also found that over 90% of respondents were satisfied with their Primary Care Physician, including ability to get appointments, travel time, and accessibility, although long travel time was the problem most frequently mentioned by those who were dissatisfied. Nearly 80% of respondents had been able to keep at least some of their specialists after enrolling in managed care, and half of respondents were referred to new specialists and services. However, respondents who were dissatisfied expressed frustration over doctors dropping out of HMO networks and fear that there would not be enough high-quality physicians available to meet their needs. The greatest concern was expressed over a lack of dentists, gynecologists, and other specialists within a reasonable travel time who are skilled at serving individuals with disabilities. Many of the persons contacted for follow-up interviews were concerned about having to switch physicians if their doctor left the HMO and about losing the network of providers with whom they had established a relationship. Respondents felt that these providers best knew the patients' case histories and complex health problems, and that new physicians may not understand the special needs of people with developmental disabilities.

While 63% of survey respondents reported that they were generally satisfied with their HMO, there were substantial complaints about the inconvenience of getting referrals for services which were needed on an ongoing basis and difficulties getting approvals for brand-name prescriptions, medical supplies and equipment, and services which the doctor had deemed medically necessary. The inconvenience of getting referrals was especially expressed by interview re-

spondents who are working parents taking care of children with developmental disabilities. Interview respondents also reported that having to travel to laboratories that are in the HMO network rather than a local facility was a source of inconvenience, and that waiting times at network labs were longer than those at hospitals. Some interview respondents reported problems getting payment for covered supplies or services, and resolving these problems often required several phone calls or letters. A few interview respondents reported that they were never able to resolve these issues and either paid for medications/supplies out of pocket or went without the supplies.

Forty percent of survey respondents reported receiving a complex needs assessment (an in-depth inventory of medical history and need for services for individuals with special health needs), but it is possible that others had received one; respondents were confused about what constituted a special needs assessment and what information they should provide to their HMO to indicate that they or their child had special needs. Therefore, it is not clear whether the HMOs were able to identify and appropriately evaluate medical needs for individuals with complex disabilities.

The response rate for the mail survey was 38%, and most were completed by a proxy for the consumer. After examining information about guardianship and living arrangements obtained from DDD for respondents and nonrespondents, we believe that parents were more likely to respond than Bureau of Guardianship guardians or community providers. Respondents were more representative of individuals who enrolled voluntarily in managed care than those who did not select an HMO and were automatically assigned to a plan.

Introduction

The New Jersey Department of Human Services, Division of Medical Assistance and Health Services (DMAHS), has provided mandatory managed care services to children under 18 and their parents with very low incomes since 1995 and to NJ KidCare and NJ FamilyCare enrollees since 1998.

Until recently, the individuals who receive Supplemental Security Income (SSI) had the choice to enroll in managed care, and those enrolled report high satisfaction with their health care. Effective October 2000, New Jersey Care 2000+ was implemented to provide managed care for Supplemental Security Income (SSI) Aged, Blind and Disabled beneficiaries, a group which includes many individuals with developmental disabilities. DMAHS has developed for New Jersey Care 2000+ a more inclusive Medicaid managed care contract that incorporates many protections for individuals with special needs. An important goal of the program is to improve access through care management services to assist consumers and their families in navigating a fragmented delivery system.

Previous studies have emphasized the importance of care coordination and a focus on preventive care in fulfilling the promise of Medicaid managed care to individuals with complex needs,¹ but have also noted problems such as too few doctors in provider networks, particularly those experienced in working with people with special needs.² Beneficiaries in Medicaid managed care have reported a lack of information about the enrollment process and confusion about how to use managed care effectively. Reviews of the sparse existing literature on managed care for individuals with disabilities have documented the concerns expressed in focus groups about difficulties with the enrollment and referral processes, as well as problems obtaining specialty services, prescription drugs, and durable medical equipment.^{3,4,5} Awareness of these issues informed planning for New Jersey Care 2000+.

The implementation of New Jersey Care 2000+ was the result of an extensive planning process which

involved both advocates and representatives of health plans, and the health plans made a strong effort to increase the numbers of providers in their networks with expertise in dealing with individuals with special needs. The original plan was to phase in participation of all aged, blind and disabled beneficiaries in tiers of counties. However, to date beneficiaries have been encouraged and assisted to enroll in managed care, but automatic assignment to a health plan for individuals who do not select an HMO has been implemented only in Camden County.

To help individuals enrolling in managed care for the first time make an informed decision, Health Benefits Coordinators (HBCs) employed by the benefits coordinating firm were trained to provide assistance to individuals with special needs and provided education and outreach through community meetings and telephone and personal assistance to consumers and families as they enrolled in managed care and selected a health plan.

When New Jersey Care 2000+ began, six health maintenance organizations (HMOs) had Medicaid managed care contracts with the State of New Jersey. All of the HMOs must abide by the same Medicaid managed care contract provisions, but each has its own provider network and its own approach to meet the contract requirements. Aetna Health, Inc. withdrew from Medicaid managed care before this survey was fielded, and New Jersey Care 2000+ participants who were enrolled with Aetna were reassigned to another health plan.

The purpose of the study was to document the transition from fee-for-service to managed care as experienced by consumers with developmental dis-

abilities and their families. The sample for this study was drawn from individuals served by the New Jersey Department of Human Services Division of Developmental Disabilities (DDD), since these individuals received all medical care, as well as mental health and substance abuse services, through their HMO rather than fee-for-service.

Between September 2002 and July 2003, researchers at the Center for State Health Policy conducted a two part study: a mail survey of 325 randomly se-

lected individuals who enrolled in New Jersey Care 2000+ between October 2000 and September 2002, followed by in-depth semi-structured interviews with 37 of the people who completed the survey. The interviews were designed to focus in depth on understanding any difficulties which individuals had experienced enrolling and receiving services from their health maintenance organization (HMO), and their problem-solving strategies for dealing with them.

Methods

The 325 completed mail surveys were obtained from a stratified random sample of 900 individuals enrolled in New Jersey Care 2000+ between October 2000 and September 2002. The survey instrument was developed by the Center for State Health Policy and administered by Schulman, Ronca, & Bucuvalas, Inc. During the second phase of the study, in-depth personal interviews were conducted with 37 individuals who completed the mail survey by researchers at the Center for State Health Policy.

Mail Survey Questionnaire

The survey instrument was developed by the Center for State Health Policy and consisted of 70 closed-ended questions and 11 open-ended questions. Items were developed by experienced survey researchers after reviewing the results of previous focus groups of individuals with disabilities discussing managed care and relevant questions from other health care surveys. The questionnaire was reviewed by the Health Care Task Force at the NJ Council on Developmental Disabilities and informal focus groups of consumers and family members to obtain expert advice about the wording of questions.

The survey asked in which HMO respondents were enrolled and how they became a member of that HMO. Subsequent sections examined their experiences with the enrollment kit and enrollment events, Health Benefits Coordinators (HBCs), membership information from the HMO, care managers, complex needs assessments, primary care providers and specialists, and knowledge of rights. At the end of the survey, we asked if respondents were willing to be

contacted for further information and asked them to provide contact information.

A copy of the questionnaire is in Appendix A.

Pretest

Fifty individuals from the sample of 900 (see section on Sample) were randomly selected for a pretest in order to discover any inherent problems with the structure and/or content of the questionnaire. During October 2002, these 50 pretest individuals were mailed an advance letter outlining the purpose of the study; a few days later a questionnaire packet was mailed to each person. This packet contained a copy of the questionnaire, an endorsement letter (printed on special letterhead), and a pre-paid business return envelope. Only minor changes were made to the questionnaire based on the pretest to make the order of items easier for respondents.

Sample

A list of 2,250 individuals served by DDD who were enrolled in New Jersey Care 2000+ between October 2000 and September 2002 was generated by DMAHS, and 900 people were randomly selected to be part of this study. Since at the time of the survey, Camden County was the only location where individuals had been automatically assigned to an HMO, we expected pure random sampling to result in very few survey responses from individuals who did not select their own HMO. Therefore, in an attempt to obtain enough responses from individuals who were automatically enrolled in an HMO to be able to analyze them separately from individuals who selected an

HMO, we oversampled Camden County by randomly selecting half of the beneficiaries in the county to be part of the sample.

Mail Survey Procedures

On 11/1/02, advance letters were mailed to the 850 remaining people selected for the study. On 11/5/02, a survey, endorsement letter, and business return envelope were mailed to each person in the sample. On 11/11/02, reminder postcards were mailed to the 835 people who had either not yet returned the questionnaire at that point or else did not have their original letter returned due to a “bad address.” Two more waves of packets were mailed (approximately one and two months after the original mailing) to any person who had not yet returned the questionnaire or did not have a “bad address.”

The overall response rate was 38.74% (313 completes out of 804 with good addresses; 46 packets were returned undeliverable with no forwarding addresses). By wave, the response rates were 24.1%,

10.8%, and 3.9% (and 26% for the one-contact pretest). A coding manager edited each returned questionnaire for errors. Questionnaires were then entered into an SPSS data entry program and 100% key verified. Completed pretest questionnaires were also data entered and combined with the main version data, providing a total of 325 completed surveys.

Follow-Up Interviews

We interviewed 37 individuals as a follow-up to the mail survey. The goal of these interviews was to obtain more in-depth information about any difficulties people had experienced during enrollment and receiving services from their HMO and the strategies they used to cope with these difficulties. We chose our sample for follow-up from those respondents who indicated a high degree of dissatisfaction with the enrollment/HMO selection process or dissatisfaction with managed care. The purpose of the interviews was to gather more information about the reasons for dissatisfaction.

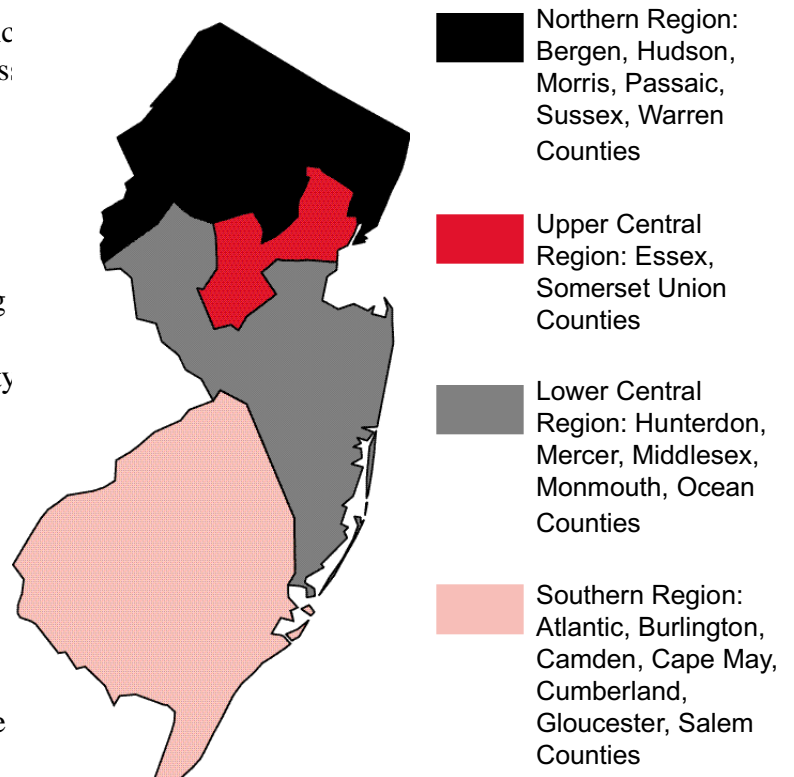
Results of the Mail Survey

First we provide a description of the characteristic of respondents to the mail survey, and then we discuss findings regarding enrollment, HMO selection, and early experiences with PCP and specialist care.

Characteristics of Respondents

Demographic Profile

We received responses from individuals residing in every county in New Jersey, with the largest percentage of respondents (11.9%) from Camden County and another 10% from Hudson County. The proportion of responses received did not differ from the sample by county. When we compare the survey respondents received from each of the four DDD service regions, overall a higher proportion of survey respondents than in the survey sample were from Northern Region. Smaller proportions were from Lower Central and Southern Regions (Figure 1). Respondents were generally representative of the survey sample, as noted in figures 2 and 3. The average age of the consumers was 29 years old, with



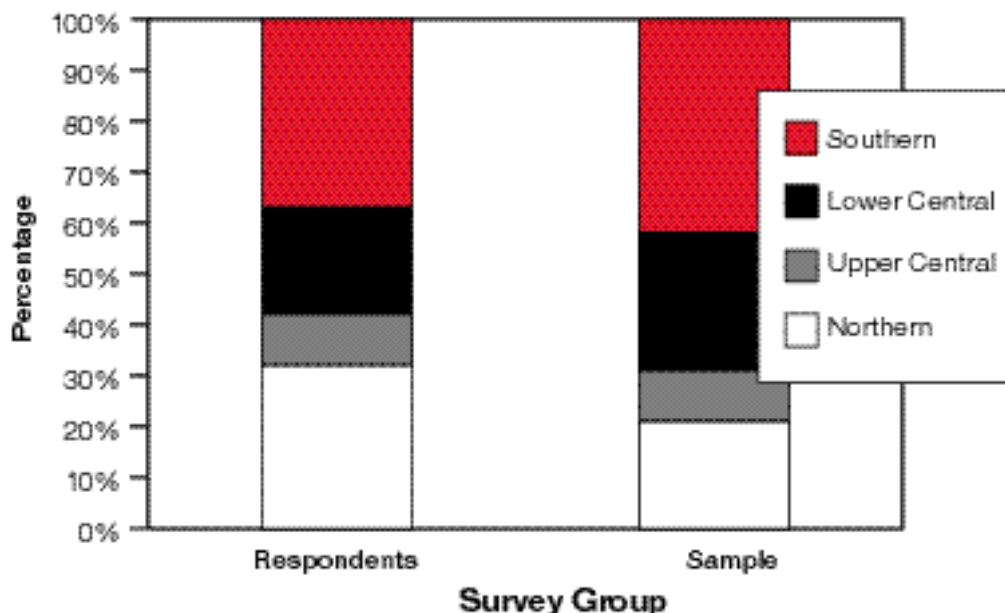
Division of Developmental Disabilities Regions

almost 36% between 20 and 29 years old and more than 50% under 30, which reflects the proportions in the survey sample. Slightly more respondents were female than in the sample (44.3% compared to 42.8%), but this difference was not significant.

We asked respondents first if they were of Hispanic or Latino origin and then about their race in an

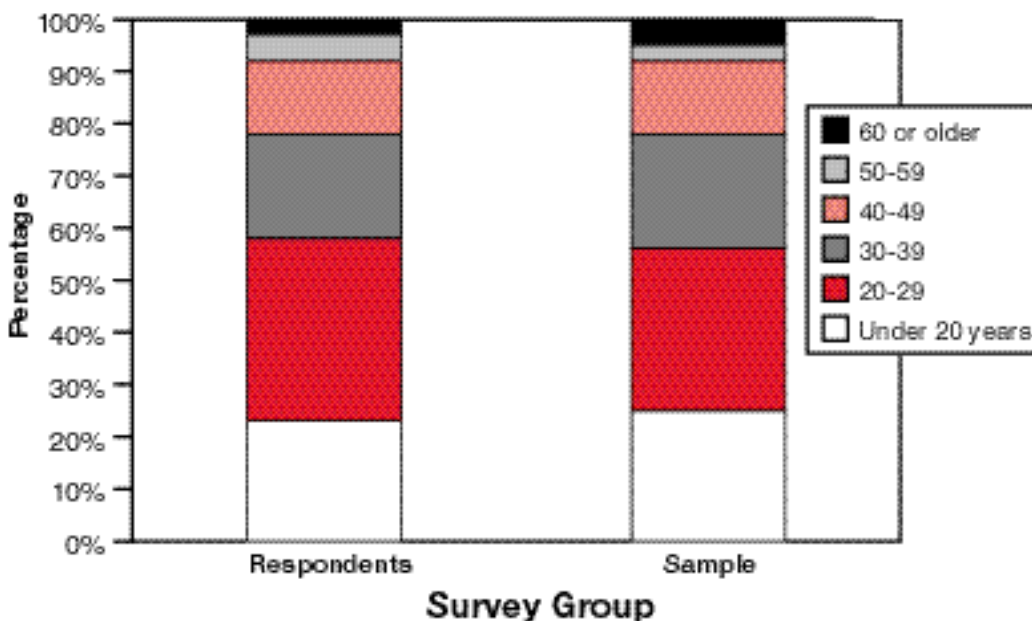
attempt to elicit more precise information about race and ethnicity. Figure 4 shows the race of respondents of Hispanic and non-Hispanic ethnicity. Hispanic/Latino was recorded as race only when the respondent wrote this answer on the survey questionnaire. Overall, respondents were predominately white (61.5%), with about equal percentages reporting that they were

Figure 1. Survey respondents and survey sample comparison by region of State.



Note: Significance measured by chi-square, $p < .01$

Figure 2. Survey Respondents and Survey Sample Comparison by Age



black or of Hispanic/Latino origin (18.2% and 17.5% respectively).

Information was not available to compare the survey respondents to the sample on other characteristics of interest, such as health care needs. Because nearly 7% of the addresses in the survey sample were unusable and unmeasured characteristics may have

made some individuals less likely to respond, the reader should use caution when extrapolating the results of this survey to the general population of individuals with developmental disabilities participating in Medicaid managed care in New Jersey.

Figure 3. Percent of respondents and survey sample comparison by gender.

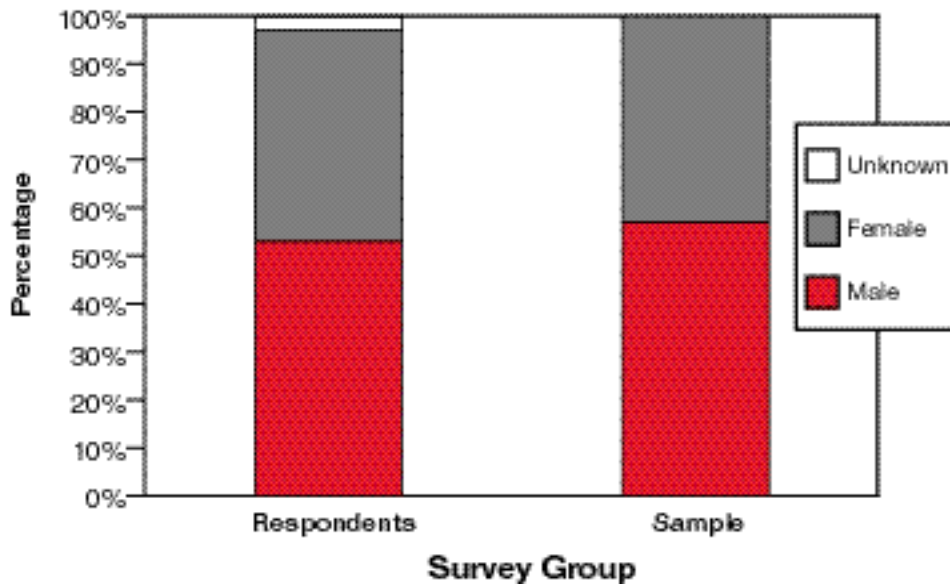
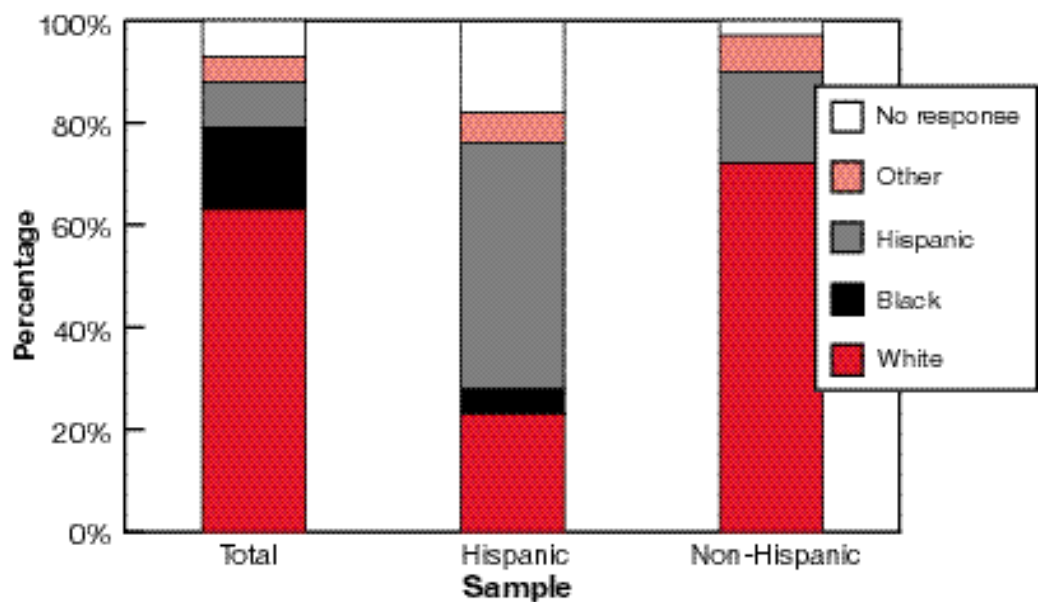


Figure 4. Racial and ethnic characteristics of survey sample (N=325).



Assistance Completing Survey

Most of the survey participants (95.7%) reported receiving help in filling out the survey. Primarily, assistance came from family members (83%), and about three-quarters (76.2%) had proxies answer the questions for them (Figures 5 and 6). Many of the consumers who had someone read the questions and write down their answers received assistance from staff members. When non-family guardians responded for a consumer, they noted that they had also received assistance from staff members. The people who assisted with the survey were well acquainted with the consumers; 88.7% of respondents reported that they saw or talked to the person who helped them daily or almost daily and nearly 95% communicated with the person at least weekly (Figure 7).

Figure 5. Who helped respondent complete the survey (N=311).



HMO Enrollment

At the time of the survey, individuals could be enrolled in one of five HMOs. About a third of the respondents (35.4%) were enrolled in Horizon Mercy and less than 10% were enrolled in either University Health Plan or HealthNet (Figure 8). One respondent was no longer enrolled in an HMO.

Figure 9 indicates the method by which respondents were assigned to their HMO. Nearly two-thirds of respondents chose their current HMO and 13% (42 individuals) originally chose Aetna, but changed plans when Aetna left Medicaid managed care. Of those, 62% (25 individuals) switched to AmeriChoice when they left Aetna.

Several of the respondents who had switched to AmeriChoice commented in response to an open-ended question about why they chose their HMO that they had originally chosen Aetna because other family members had coverage with Aetna and they were familiar with the plan. Several respondents indicated that they felt they didn't have any choice when the change occurred; a typical comment is "didn't have any choice, did choose but was changed." However, two individuals indicated that they selected AmeriChoice because there was a health center nearby.

Figure 6. Type of help respondents received with survey (N=273).

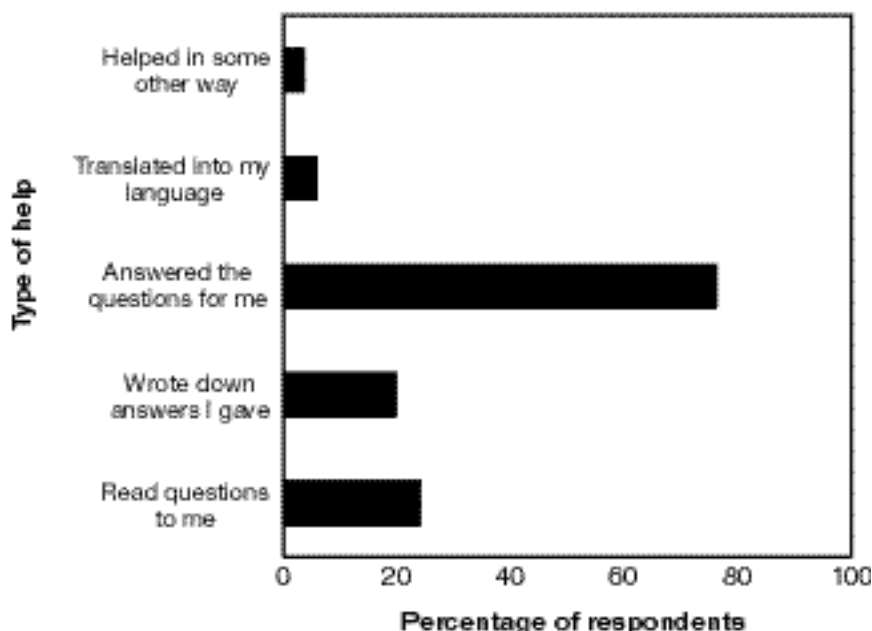


Figure 7. How often consumer sees or talks to person who helped with survey (N=231).

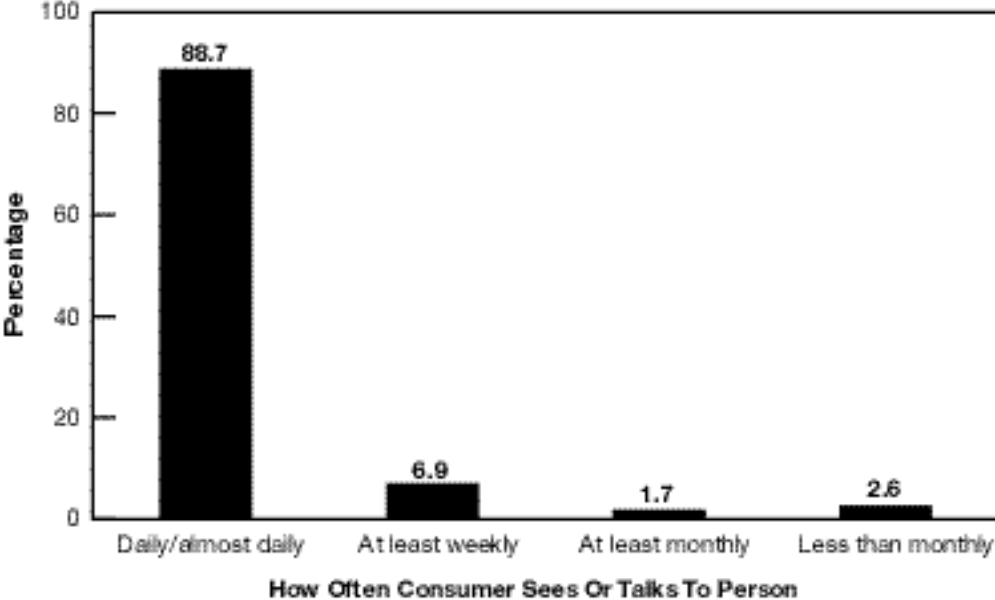


Figure 8. HMO enrollment reported by respondents (N=325).

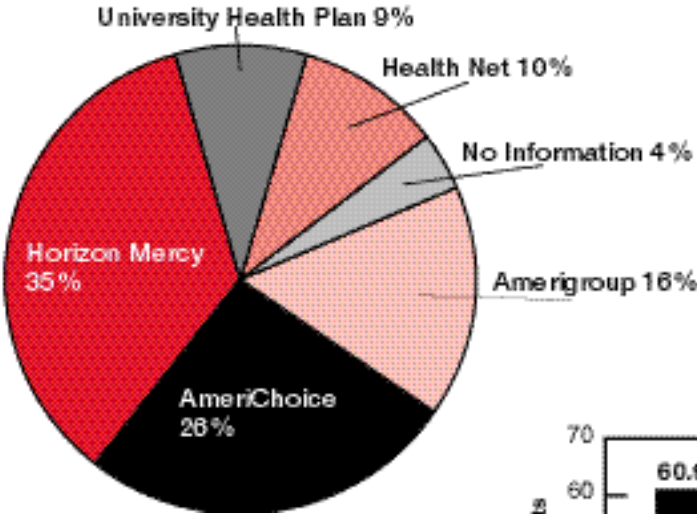
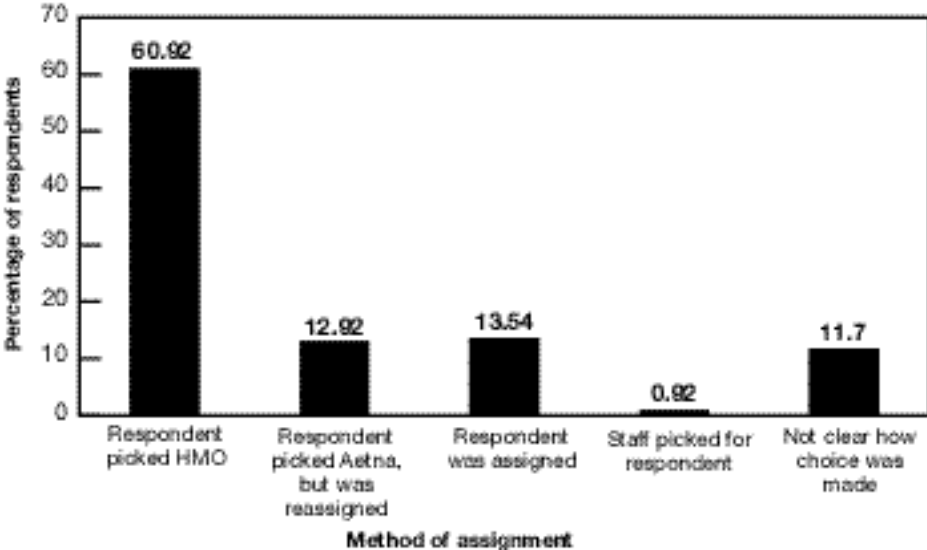


Figure 9. Method of assignment to an HMO reported by respondents (N=325).



About 14% of respondents indicated that they were assigned to an HMO; however, a number of these individuals did not live in Camden County, the only county where automatic assignment was implemented. From other information provided on the survey or by making follow-up phone calls, we were able to determine that many of these individuals received recommendations from a medical professional, a staff person, or an HBC, and the respondent chose the recommended plan. Therefore, these individuals were not automatically assigned to an HMO. Out of 38 respondents from Camden County, only ten indicated that they were automatically assigned.

Figure 10 indicates the HMO selected by those individuals who indicated that they picked their own

HMO. Forty percent of the respondents who chose their own plan selected Horizon Mercy, and about 20% respectively chose AmeriChoice or Amerigroup.

Figure 11 shows the length of time respondents had been enrolled in an HMO at the time they completed the survey. On average, respondents had been enrolled in an HMO for 21 months, and 49.4% of respondents had been enrolled for between one and two years. This suggests that respondents may not recall events at enrollment clearly, but that many respondents have had the opportunity to build up some experience with services under managed care, which was substantiated in the information we obtained during interviews.

Figure 10. HMO membership of respondents who reported selecting their own plan (N=193).

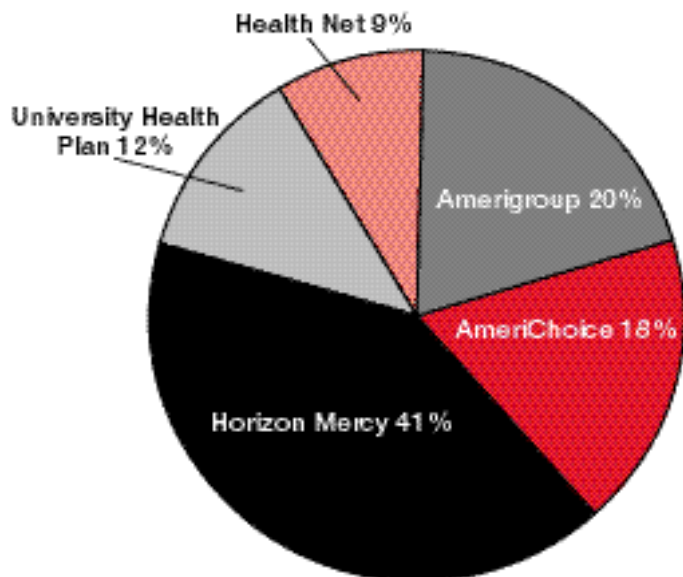
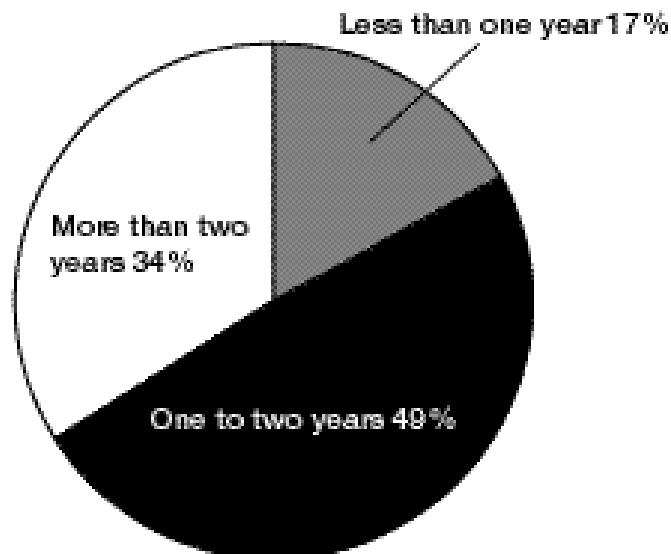


Figure 11. Length of time enrolled in their HMO reported by respondents (N=263).



Enrollment in New Jersey Care 2000+

In this section, we present findings about the process of enrollment and selecting an HMO.

Enrollment Kit/Event

Over 80% of survey respondents report receiving an enrollment kit in the mail, and 82% of these report that it was ‘very or somewhat easy’ to understand the information provided (Figures 12 and 13). Blacks and Hispanics were no more likely than whites to say that the information provided in the kit was difficult to understand. Nearly 80% reported that they or their

family attended an enrollment event (Figure 14). Those who attended came from all parts of the state. Of those consumers who reported that they or their family attended, 80% were under age 40. About a quarter were Hispanic and 18% were black; these individuals were no less likely to attend an event than other groups.

In follow-up interviews with individuals who said that they found the enrollment kit difficult to understand, people commented that it was hard to complete the forms if they needed to provide information about a large existing network of providers.

Figure 12. Respondents who report receiving an Enrollment Kit by mail (N=325).

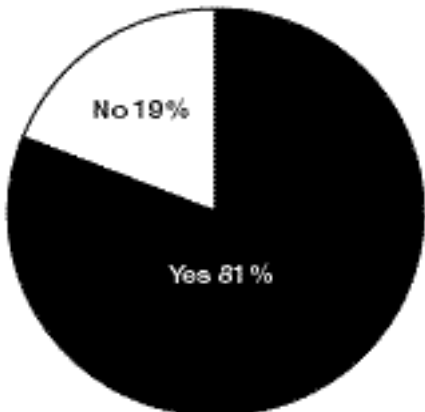


Figure 13. Perceptions of how easy it was to understand Enrollment Kit (N=236).

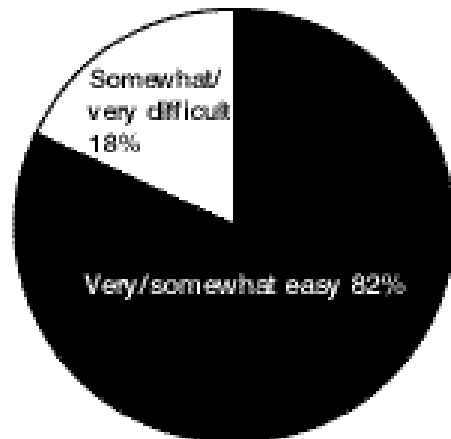
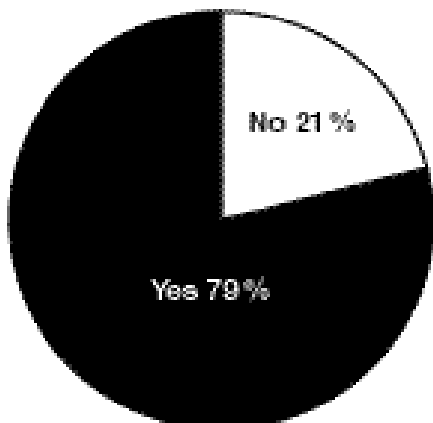


Figure 14. Respondents who report attending an enrollment event (N=325).



Selecting an HMO

About two thirds of respondents found it very or somewhat easy to select an HMO, while about 13% report that they never tried to select one (Figure 15). People who had help selecting an HMO and filling out forms got it most frequently from family members or guardians (Figure 16). For those who did not receive help from a family member or guardian in selecting an HMO, the most frequent source of help was a professional such as a doctor, nurse, or social worker (Figure 17). Most of those who said they did not receive help were parents enrolling their children.

Figure 15. Responses to how easy it was to select an HMO (N=315).

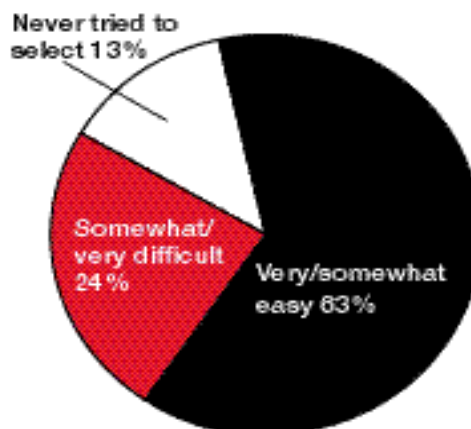
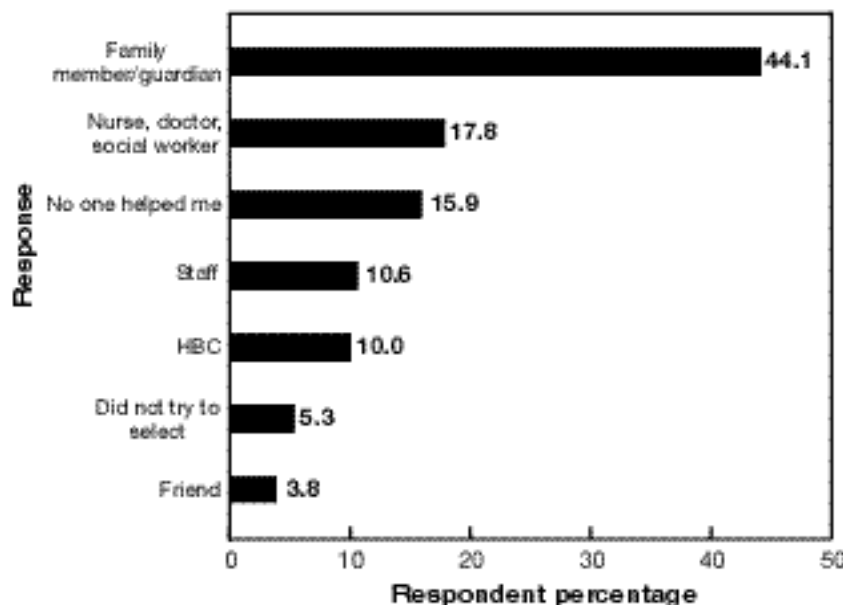
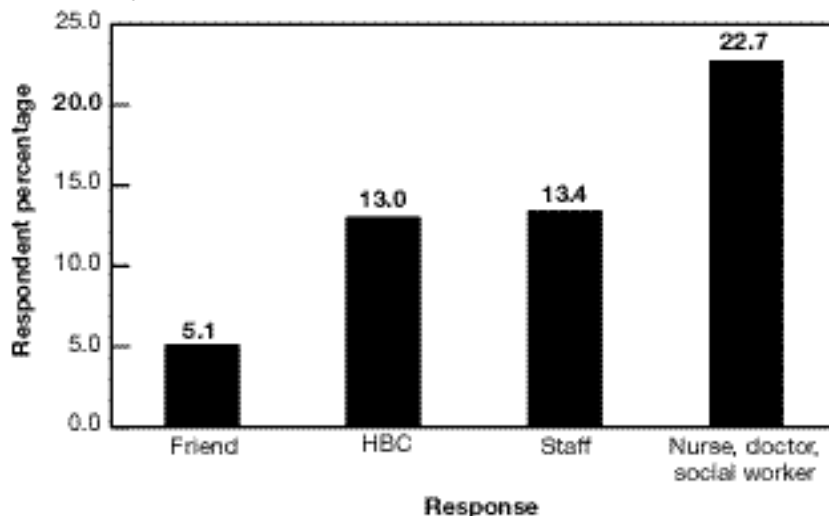


Figure 16. Responses to 'Did anyone help you select your HMO?' (N=320).



We asked respondents why they selected or chose not to select their HMO, and 269 individuals responded to this question. Respondents were allowed to write in an answer if none of the responses provided was acceptable to them. By far, the most frequent response for choosing an HMO was because an individual's primary doctor or specialist was a member

Figure 17. For respondents who did not receive help from family: Responses to 'Did anyone help you select your HMO?' (N=216).



of a particular network (69% of respondents). A substantial group of respondents (18%) noted that they hoped to receive new services. As mentioned above, many people received a recommendation from a health care professional. Some individuals mentioned that there were few available doctors in their area. Some parents noted that they chose for their child the same HMO which they had for themselves.

Individuals who did not select a plan noted that they found the process confusing, that they did not perceive any real difference between the HMOs, or that they simply did not want to be in managed care or found enrollment too much of a hassle. One parent commented, “Was caring for my disabled child and don’t have time to fill out piles of paperwork.”

The following comments are representative of the range of written responses about why people selected their HMO:

“Hospital takes it where (name) goes and his doctor’s there.”

“It was recommended by speech doc.”

“Nurse knows which plans pay the least amount.”

“That’s the insurance the hospital and clinic

accept and heard it was the best. We didn’t want to change clinic.”

“I was told that it was the one that had the most MD participation.”

“I thought doctors were in plan, but would not take Medicaid coverage; however I am pleased with the doctors I have selected for (name).”

“Has parents in Horizon Medicare Blue.”

“Choices available in Sussex County were limited.”

“Horizon Mercy’s reputation.”

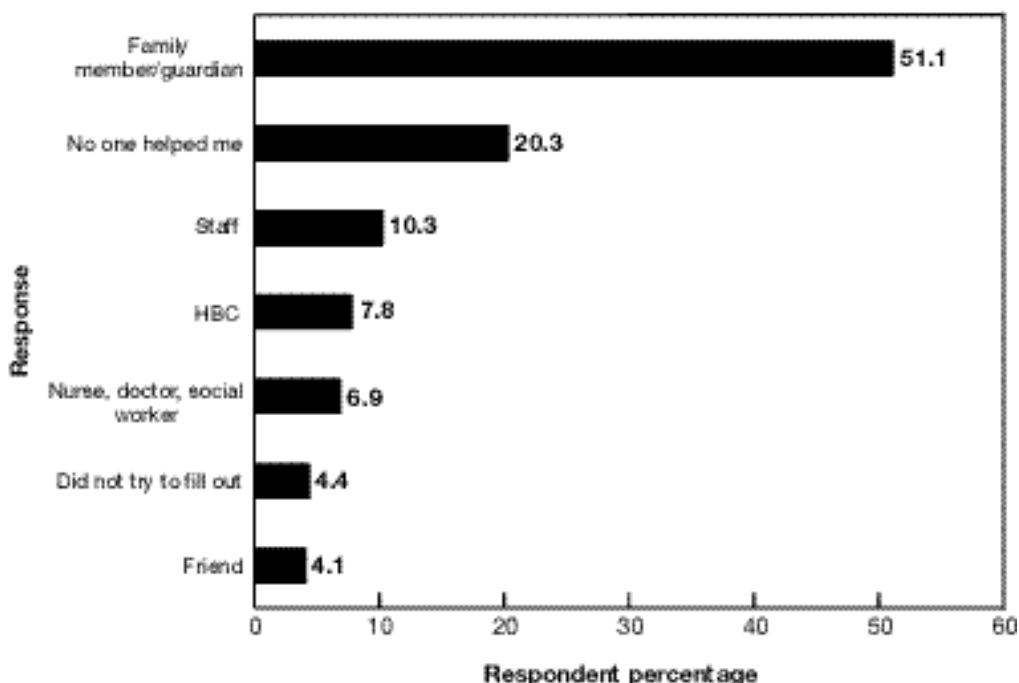
“None seemed any better than others.”

“Agency does not make it easy to pick an HMO.”

“Had to choose it—wasn’t able to choose none.”

Slightly over half of respondents reported that a family member or guardian had helped them to complete the enrollment form, and 10% received help from staff (Figure 18). While nearly a third of respondents said that no one helped them, we determined from other information on the questionnaires and follow-up phone calls that most of these individuals were parents completing forms for their children.

Figure 18. Responses to ‘Did anyone help you fill out the enrollment forms?’ (N=319).

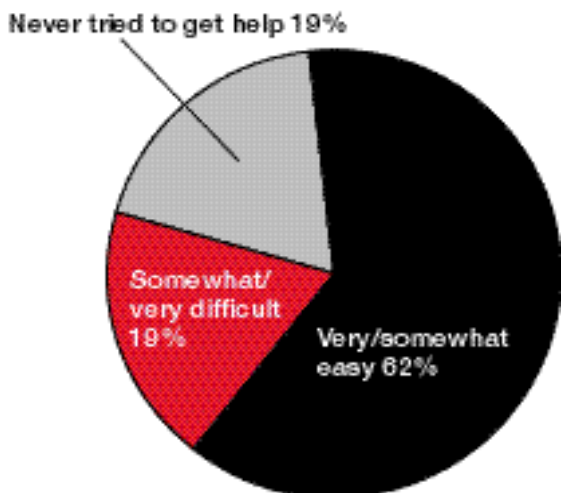


Most people (62%) reported that it was very easy or somewhat easy to understand where to get help with the enrollment process, while 19% reported that it was somewhat or very difficult (Figure 19). Another 19% reported that they never tried to get help.

Experience with Health Benefits Coordinators (HBCs)

Nearly half (49%) of respondents reported speaking to an HBC to get information or assistance with enrollment (Figure 20). Of those 159 respondents,

Figure 19. Responses to 'How easy was it to understand where to get help with the enrollment process?' (N=313).



56.5% reported that they reached an HBC after one or two calls; however, 22% reported calling more than three times (Figure 21).

Thirty percent reported that they had a difficulty such as dealing with voice mail, having to transfer, or waiting too long (Figure 22). We cannot identify if the problems occurred during a period when the HBCs were experiencing a higher than expected volume of calls (e.g., when NJ FamilyCare was receiving a high volume of applications).

Figure 20. Responses to 'Did you speak with a Health Benefits Coordinator?' (N=325).

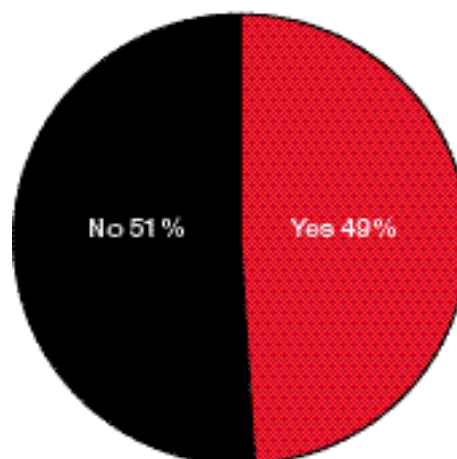
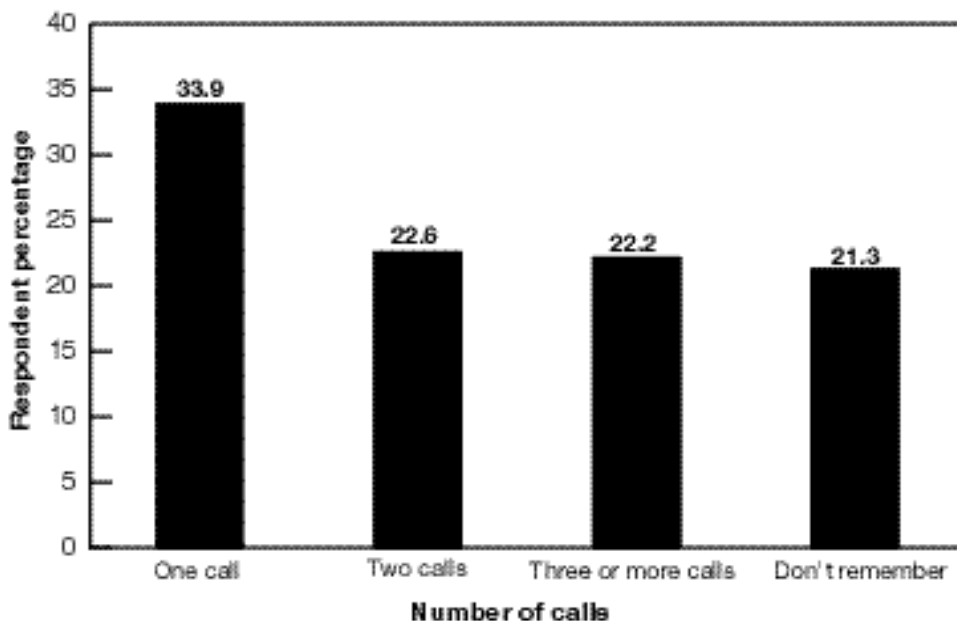


Figure 21. Number of calls before respondent spoke to an HBC (N=159).



Ten percent of respondents reported that an HBC helped them select their HMO, and about eight percent reported that the HBC helped them complete the enrollment forms. When we called individuals who said they were automatically assigned but did not live in Camden County to check their responses, some said that the HBC ‘assigned’ them to an HMO, but these appeared to be individuals who were having difficulty making a decision.

The most frequent issue for respondents who called an HBC was identifying HMO networks for their doctors, specialists, pharmacy or hospital. When asked, ‘How helpful was the health benefits coordinator,’ over 80% reported that they were Very Satisfied or Satisfied (Figure 23). Those who were not satisfied generally said that the information about which providers were in a particular network was incorrect.

Only 37 respondents reported that they were dually eligible for Medicaid and Medicare. Of these, half reported asking an HBC whether they needed to enroll in managed care (Figure 24), and 15 reported that the HBC didn’t know or told them yes. Nearly a quarter of the 159 respondents who spoke to an HBC reported being told information that they later found out was not correct (Figure 25); in follow-up questions, 29% of these respondents said that this incorrect information was about provider membership in HMO networks. A few mentioned that they later felt that they had not been able to receive services as easily as they were told by the HBC, but did not specify which services

were a problem.

These comments are typical of the comments respondents made about incorrect information from the HBC:

“Doctor I was given no longer accepted AmeriChoice.”

“Would not be refused service by doctors in practice and my daughter was.”

“1) You can see any doctor you need.

2) No mention of ‘one time only’ if doctor was not a participant in my HMO.”

“Referrals are only good for 30 days. I was told I could get a few and won’t have to keep going to the doctor for more.”

Figure 23. Responses to ‘How helpful was the Health Benefits Coordinator in providing information about Provider Networks?’ (N=98).

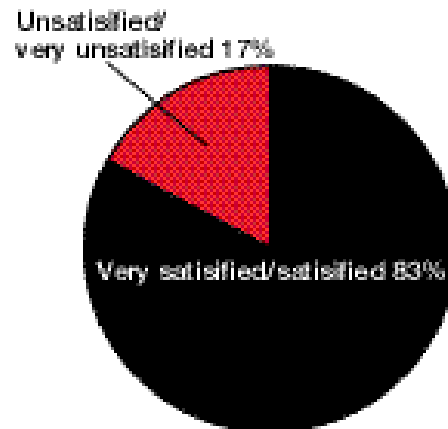


Figure 22. Respondents reporting difficulties when calling an HBC (N=159).

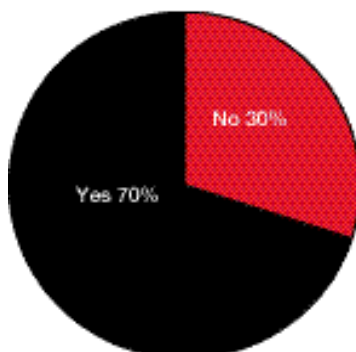


Figure 24. Respondents with both Medicaid and Medicare who asked HBC if they needed to enroll (N=37).

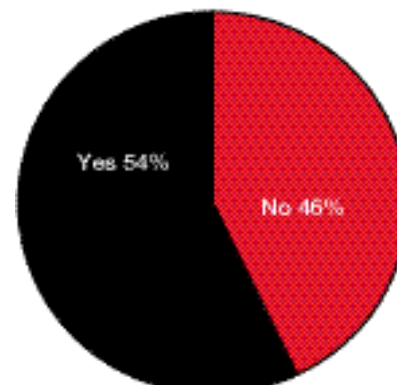
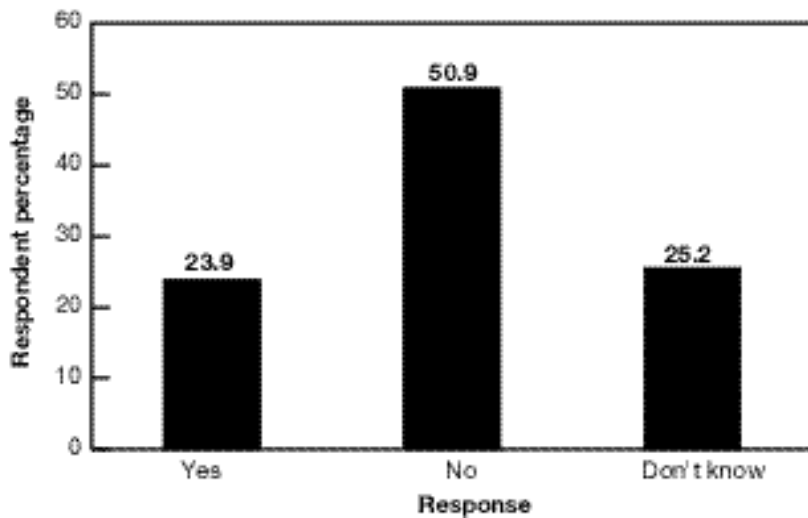


Figure 25. Responses to 'Were you told any information that you later found out was incorrect?'



Experience with HMOs
Notification and Materials

The majority of respondents (90.8%) received some sort of notification that they were enrolled in their HMO in the mail or via a welcome call (Figure 26). Slightly less than 5% did not remember receiving confirmation from the HMO that they were enrolled in their plan. The small number (0.9%) who were classified as 'Other' responded that that they called the HMO to ask or their doctor was notified that they were enrolled.

Seventy percent of respondents said that they received a member handbook from their HMO; approximately twenty percent reported that they did not receive one (Figure 27).

A little over half of the respondents (52.9%) reported that they called their HMO to ask questions (Figure 28). About one-third (31.4%) did not have to wait to speak to someone when they called, and 32% waited about 5 minutes (Figure 29). Nearly one-third (32%) reported that they had to wait ten or more minutes for a response.

Figure 30 shows that most respondents did not have any problems receiving their ID cards, but those who did had problems receiving their HMO card (12%) as opposed to their Medicaid card. A few individuals in each HMO indicated problems receiving their HMO card, but none of the health plans had significantly more problems with this. A few indi-

viduals noted that they had lost their HMO card, and it took a long time to get a replacement.

Respondents were asked to rate their overall experience enrolling in their HMO on a scale from 1 (worst) to 5 (best). The average rating overall was 3.5, with two plans slightly above and three plans slightly below average (Figure 31). No plan was significantly different from the average, although Amerigroup was significantly lower than Health Net and Horizon Mercy ($p < .05$).

Figure 26. Responses to 'How did the HMO let you know you were enrolled?' (N=325).

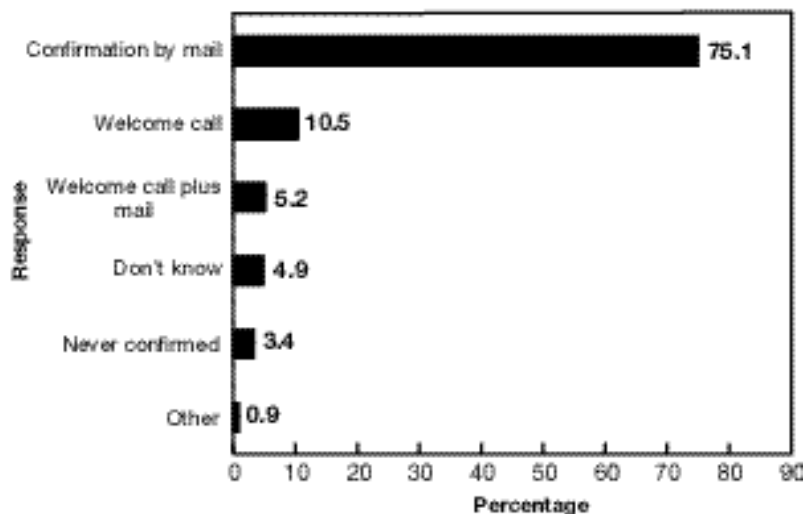


Figure 27. Respondents who received a Member Handbook from HMO (N=325).

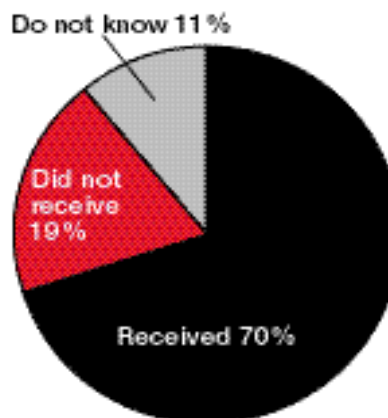


Figure 28. Respondents who called their HMO to ask questions (N=325).

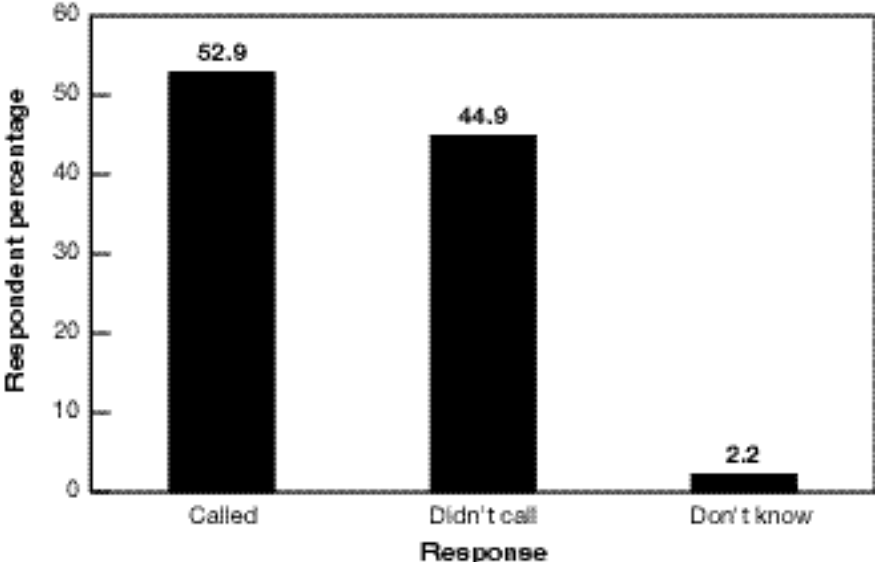


Figure 29. Responses to 'How quickly did you reach the person you needed at your HMO?' (N=172).

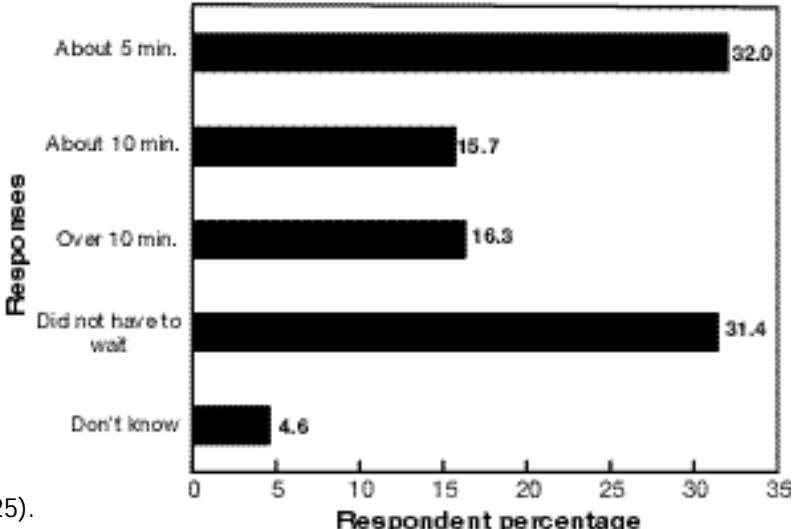


Figure 30. Rating of overall satisfaction with HMO (N=325).

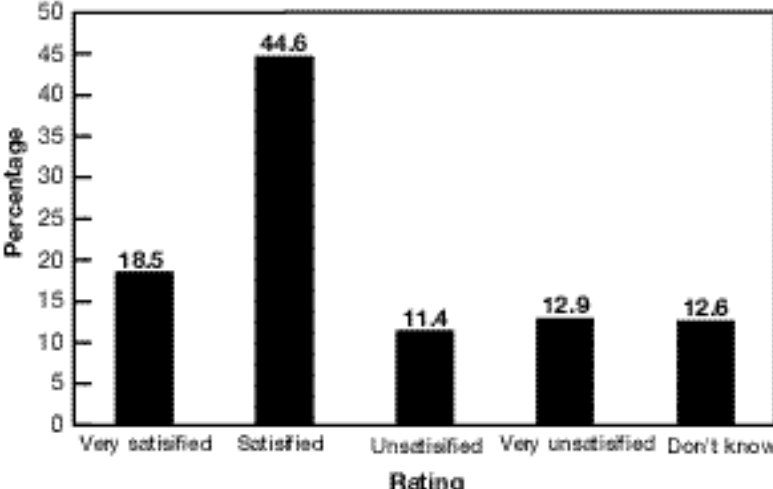
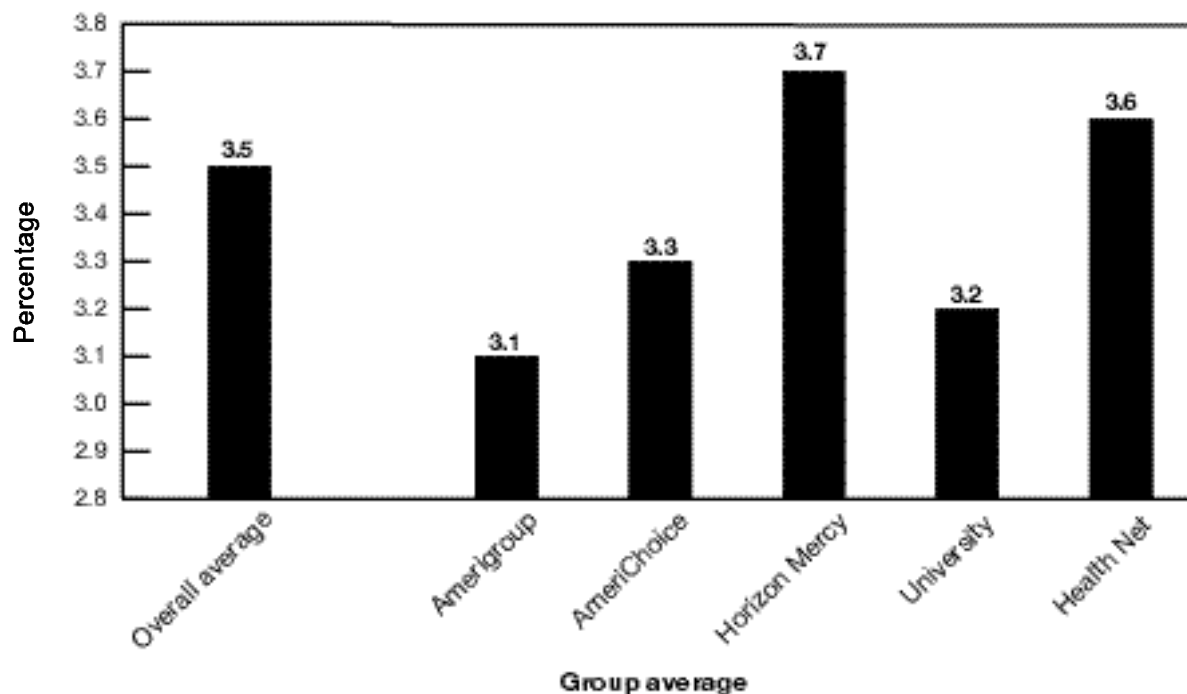


Figure 31. Rating of overall experience enrolling at HMO (N=297).



Experience with Care Managers

A potential benefit of managed care is the ability to improve access through care coordination for those individuals with complex health care needs. Individuals vary in their need for help in coordinating services depending upon the number of health services they use, whether or not they have an existing network, and the personal supports available to them to help coordinate care. Navigating a fragmented system with a shortage of providers experienced in dealing with people with special needs can be difficult and frustrating. At the time of the survey, 52.6% of the respondents reported being linked with a care manager after they enrolled in their HMO, and 43.7% had not received a care manager (Figure 32). Of those who were linked with a care manager, 76% were linked within 30 days of enrolling, and 15.2% were linked after more than 30 days.

Figure 32. Linkage with Care Managers at HMO (N=325).

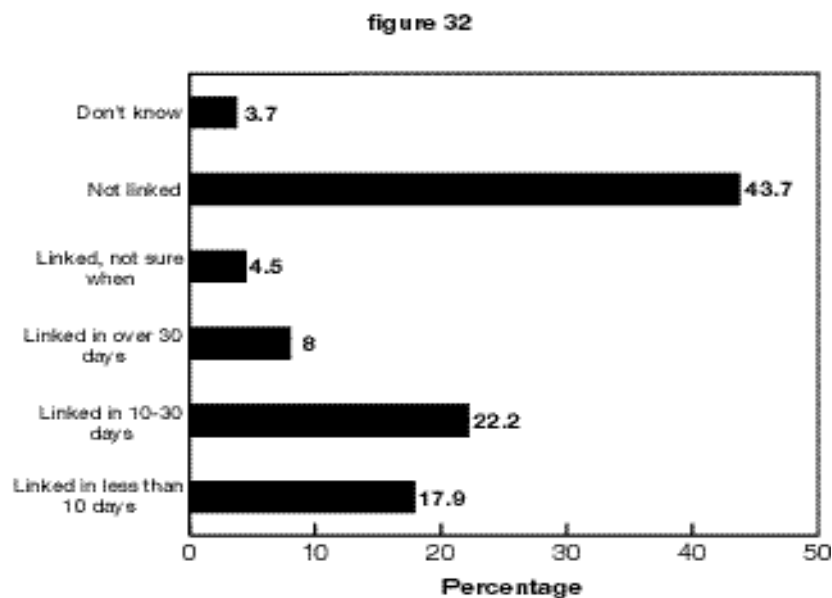
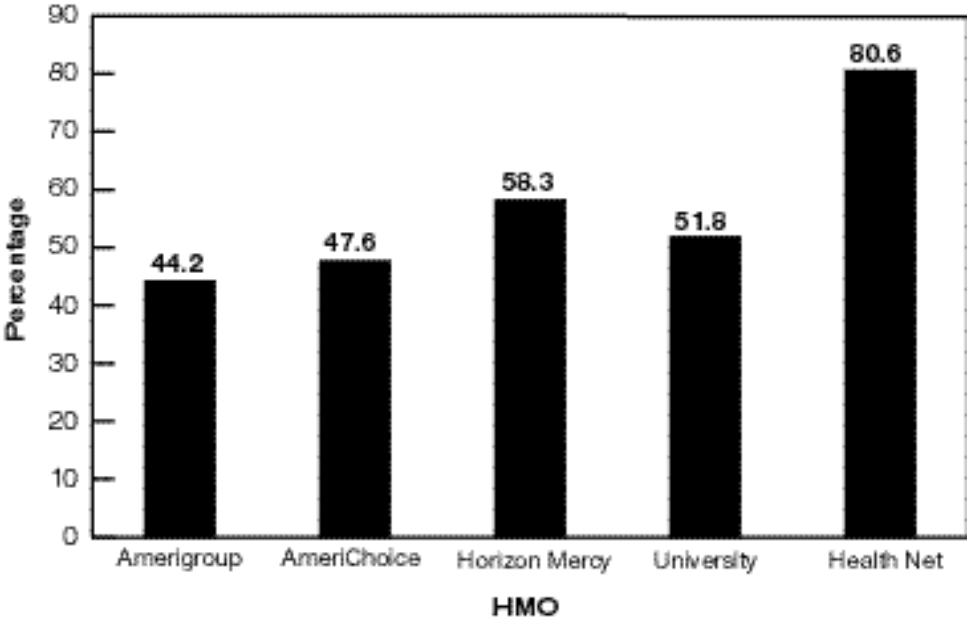


Figure 33. Individuals linked with Care Managers by HMO (N=300).

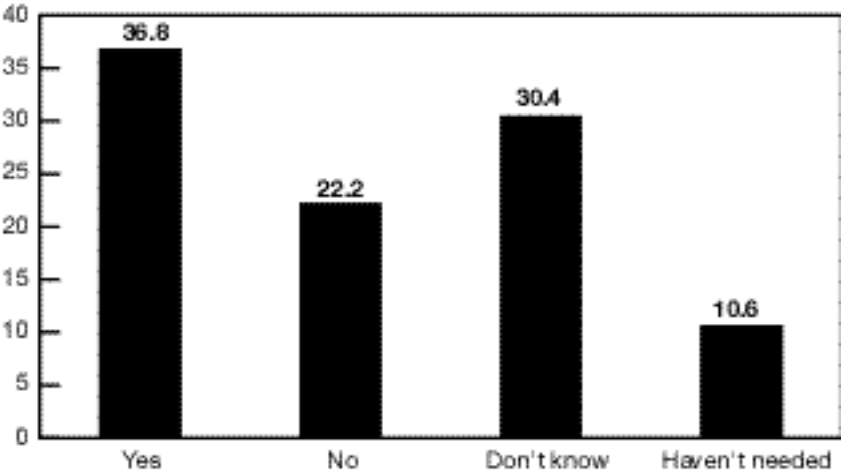


Health Net had significantly more individuals who reported linkage with care managers than average, followed by Horizon Mercy and University Health Plan (Figure 33). The remaining two plans had fewer than half of survey respondents linked.

The managed care contract provides for care management systems to ensure that all required services which are identified by a needs assessment are provided. Some individuals may require services not available through the HMO; therefore, care managers may coordinate with providers outside the network.

Among the 171 respondents who had care management, 36.8% said their care manager offered to help them get any health or medical services that their HMO doesn't cover (Figure 34).

Figure 34. Responses to 'Has your care manager offered to help you get any health and medical services you need, but your HMO does not cover?' (N=171).



The majority (84%) of the respondents said they were either very satisfied or satisfied with their care manager (Figure 35). The number of individuals who had received care management was not sufficient to detect differences in satisfaction with care management between the HMOs, but over 75% of respondents in each HMO were very satisfied or satisfied.

Several individuals added written comments to their survey responses indicating how helpful their care manager had been; in many instances the care manager was listed as the best part of being in their HMO. Several individuals listed their care manager by name. Some sample comments:

- “The special care coordinator took care of finding and arranging for a pediatric dentist.”
- “Special needs coordinator extremely helpful.”
- “(Name) has a social worker from Mercy that helps a lot.”
- “Special needs case manager—she goes the extra mile to help my son.”

However, there were a few negative comments from the individuals who were not satisfied, such as:

- “Case worker called and said she was always available, but haven’t been able to get in touch at all. Very stressful!”
- “My care manager has been gone and no one has been able to give me the name of a new one.”

Experience with Complex Needs Assessments

We asked respondents how soon after enrollment they had received a complex needs assessment. Over 40% reported receiving a complex needs assessment, but nearly 30% had not received one (Figure 36). The majority of those who received an assessment (85%) received it within thirty days of enrollment. Of those who report that they did not receive a complex needs assessment, about 65% had kept their previous doctor after enrolling in managed care. During interviews, we found that many individuals were not sure what a complex needs assessment was and did not know whether or not it was done by the doctor or by the care

Figure 35. Overall satisfaction with Care Manager (N=171).

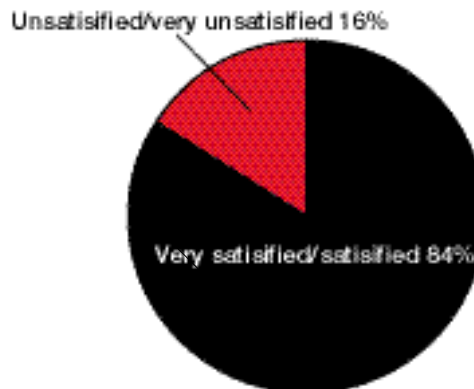
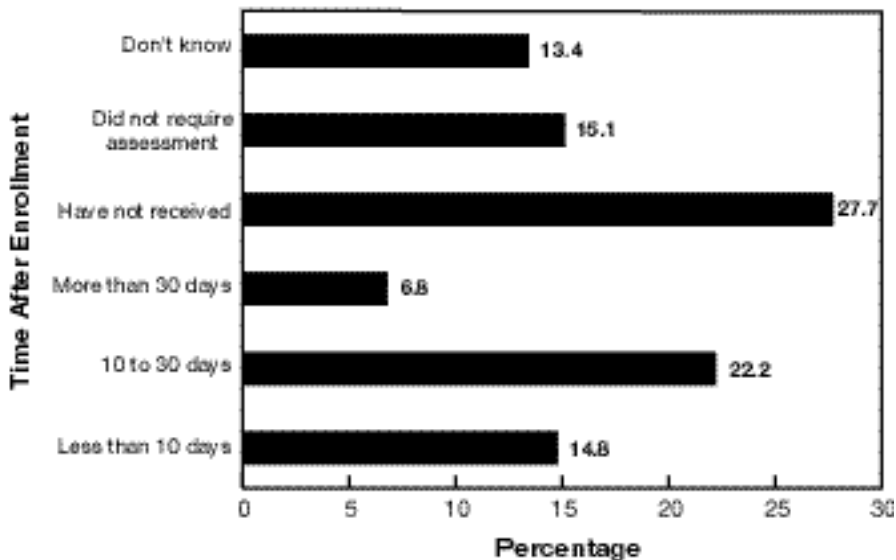


Figure 36. Length of time after enrollment until Complex Needs Assessment done (N=325).



manager. Therefore, some individuals may have received an assessment even though they did not report one. However, a small number of parents specifically commented on receiving a complex needs assessment for their child from their care manager and stated that, after the assessment was completed, it was much easier to obtain needed care for their child.

We asked respondents to rate their experience during the complex needs assessment on a scale from 1 (worst) to 5 (best). The average rating was 3.6, and over 90% rated the experience as 3 or better (Figure 37).

Figure 37. Rating of Experience with Complex Needs Assessment (N=121)

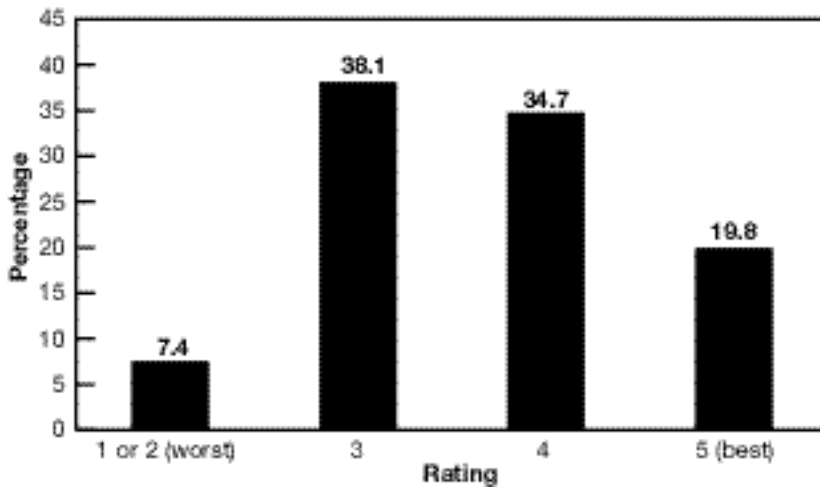


Figure 38. Respondents who kept their previous doctor as PCP (N=306).

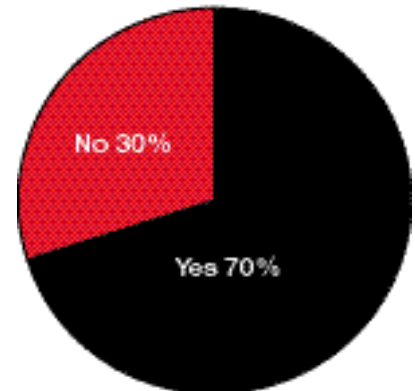
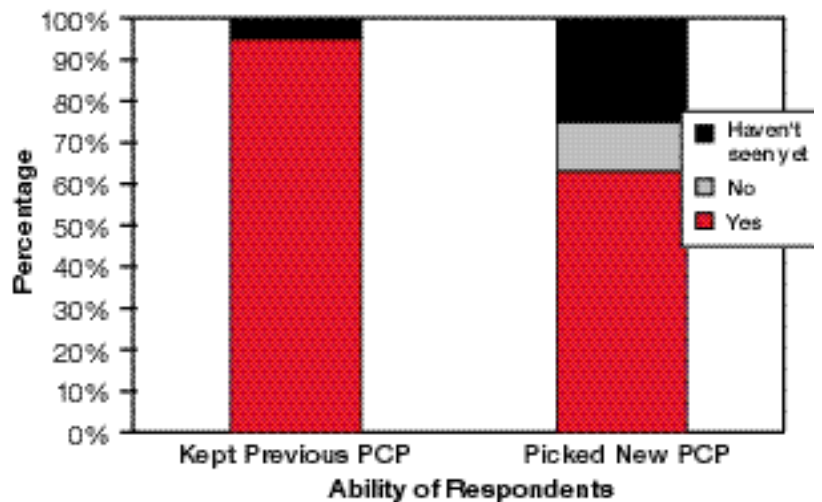


Figure 39. Ability of respondents to see PCP as often as wanted (N=321).



Experience with Primary Care Provider (PCP).

Almost 70% of respondents were able to keep their previous doctor, nurse practitioner, or specialist as their PCP when they joined the HMO (Figure 38). Among the HMOs, the percentage who kept the same PCP ranged between 60% and 70%, with no significant differences between plans.

Overall, 85% of respondents said that they had been able to see their PCP as often as they wanted. There were no significant differences between the HMOs. Figure 39 shows that individuals who selected a new PCP when they joined managed care were much more likely to say that they had not been able to see their PCP as often as they wanted or that they had not yet seen their PCP.

Figure 40 shows the number of times individuals reported seeing their PCP since enrollment. About half had seen their PCP one to four times and another quarter had seen their PCP five to twelve times. A relatively small number had seen their PCP more than 12 times.

Figure 40. Number of times individuals had seen PCP since enrollment (N=325).

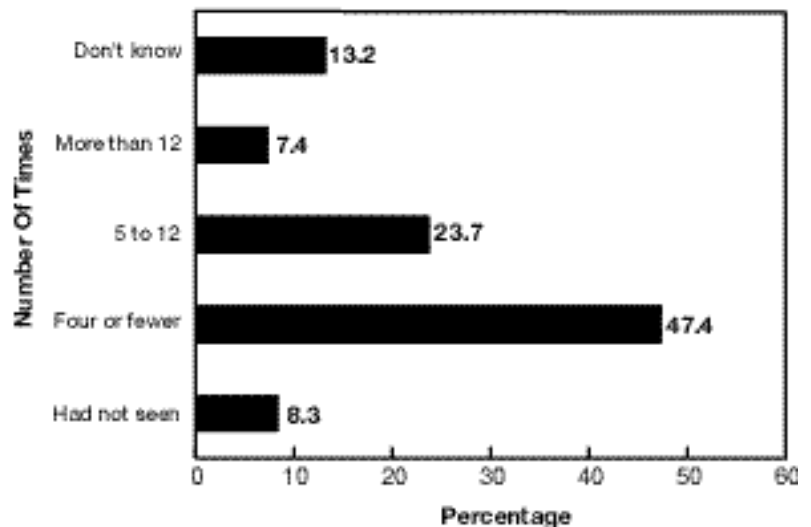


Figure 41 shows ratings of satisfaction with the PCP, the office staff, time to get appointments and travel to the PCP’s office, and responses to issues of language and culture. Overall, satisfaction with PCPs was very high, with more than 90% of respondents very satisfied or satisfied with all aspects of their experience with their PCP. Travel time was the most frequent problem mentioned by those who reported dissatisfaction.

Experience with Specialists

Respondents were asked if they had been able to keep their specialists when they joined their HMO, about new referrals, and about satisfaction with time to get appointments and travel to specialists. About one third of respondents were able to keep all of their specialists when they joined the HMO; approximately a quarter were able to keep some of their specialists, and 15.4% were not able to keep any of their specialists (Figure 42). Nearly a quarter of respondents did not have any specialists prior to enrolling in the HMO. Individuals enrolled in Horizon Mercy were significantly more likely to have kept previous specialists.

Figure 43 shows that nearly half of respondents had been referred to new medical or dental specialists since they joined their HMO. About 13% had been referred to doctors outside of their HMO network and about 7% had been referred to new services. A variety of new services were listed by those individuals, including dental, dermatology, and over-the-counter drugs. The most frequently mentioned new services were transportation, medical supplies and mental health services. Several respondents used the opportunity to reiterate the value of care management; one said “very helpful care manager; couldn’t be happier.” Eighty percent of those who received new services indicated that those services were very important to them.

Figure 44 shows satisfaction with time to get appointments and travel to specialists. Approximately 87% of respondents were either very satisfied or satisfied with how quickly they could get an appoint-

Figure 41. Reports of satisfaction with PCP, customer service and travel.

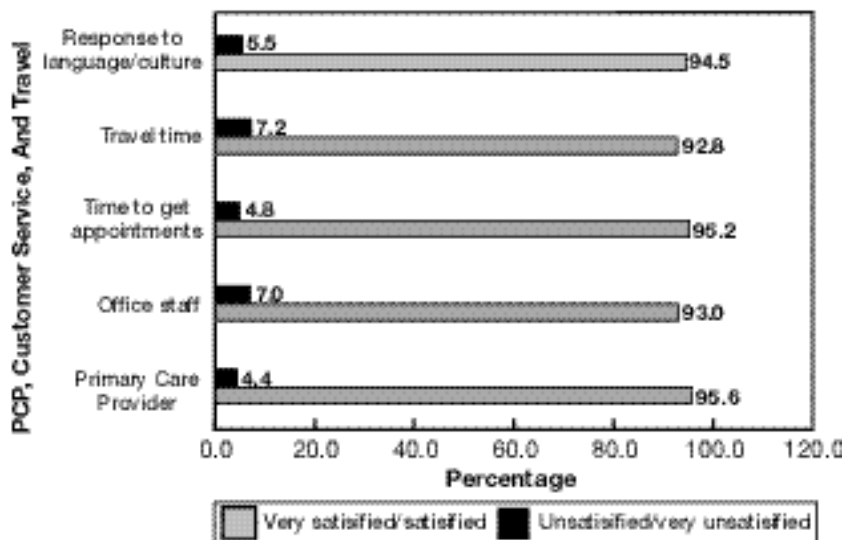


Figure 42. Responses to ‘Were you able to keep your specialists when you joined the HMO?’

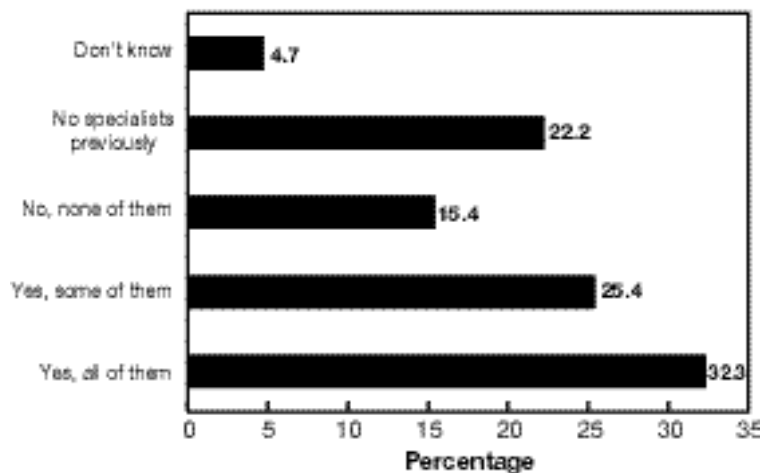


Figure 43. Reports of referrals since joining an HMO (N=325).

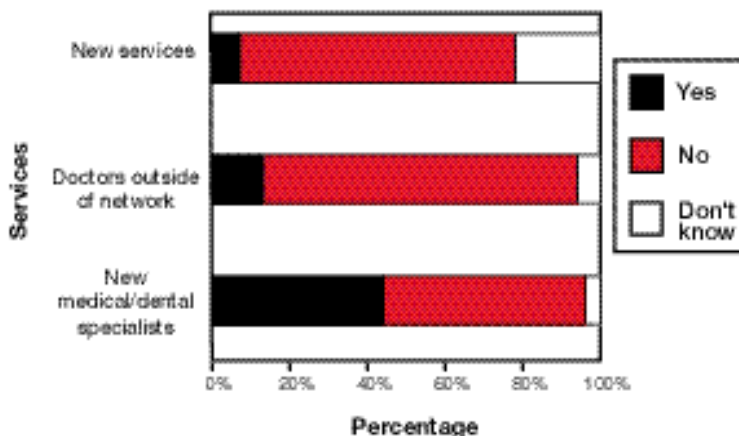
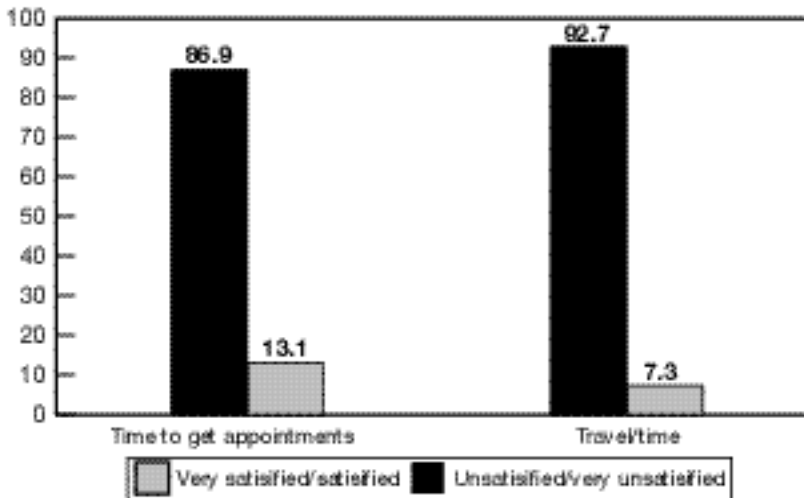


Figure 44. Rating of satisfaction with convenience of specialists (N=222).

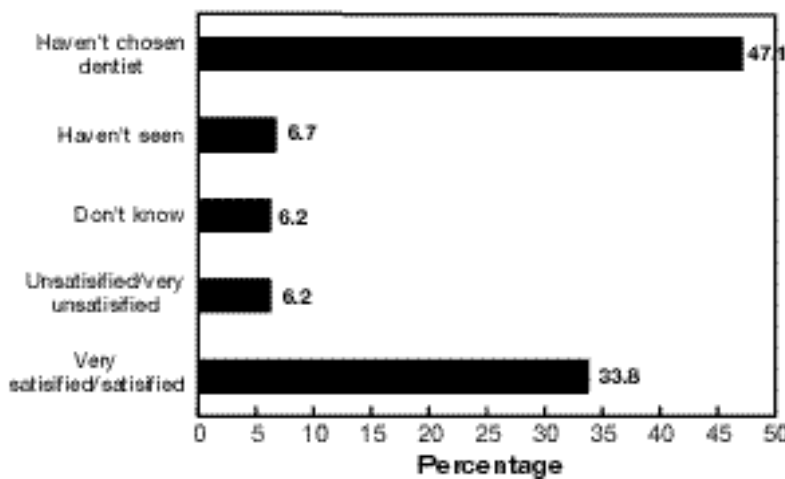


ment with a specialist, and about 93% were either very satisfied or satisfied with the time it took to travel to see specialists.

Experience with Other Services

We asked respondents about their experience with dental, mental health, and pharmacy services. A little over half of the respondents had chosen a dentist since joining their HMO. Of those who had seen their dentist, two-thirds were either very satisfied or satisfied with their dentist, with the remainder approximately evenly divided between those who were either unsatisfied or very unsatisfied, those who didn't know, and those who had not yet seen their dentists (Figure 45).

Figure 45. Rating of satisfaction with dentist (N=325).



Some individuals in all HMOs had chosen dentists and visited them, but the numbers were not sufficiently large to compare satisfaction among the plans. Inability to find a dentist was reported by about 5% of respondents as the worst part of their HMO, as indicated by the following sample comments:

“Have a hard time getting a good dentist.”
 “Worst part of HMO is dental—not enough participating.”
 “Special needs dentists—not enough.”

Figure 46. Reports of ability to get mental health/substance abuse and crisis services (N=325).

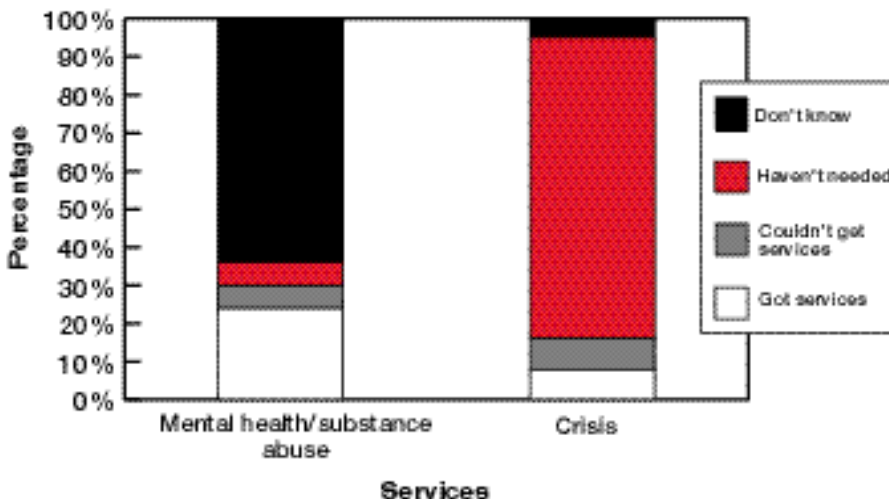


Figure 46 shows responses to the questions about mental health and crisis services. Fewer than 30% of respondents reported needing mental health/substance abuse services since joining their HMO. A little over a quarter of respondents who reported needing mental health or substance abuse services said that they could not get the services they wanted. Only 20% of all 325 respondents reported needing crisis services, but half of those persons who reported needing crisis services were not able to get these services.

The survey occurred before September 1, 2003, when all prescription medications were carved out of managed care and paid through the Medicaid fee-for-service system. Therefore, the responses to the survey questions about pharmacies and medications reflect previous policy regarding prescriptions medications.

Most respondents (82%) did not have to change pharmacies when they joined their new HMO. Overall, the majority of respondents (96%) were very satisfied or satisfied with their new pharmacy, but Figure 47 indicates that those who changed pharmacies were less satisfied than those who did not change.

More than half of the respondents were able to get brand-name drugs if required by their doctor (Figure 48). Another 16% had not required drugs yet, but 20% reported that they were not able to get brand-name drugs. Many respondents who were not able to get brand-name drugs experienced frustration, as illustrated by the following comments:

“I am angry because I have to take generic drugs. I have bad side effects with generic drugs.”

“HMO does not cover medications that work well. Substitutions are inferior or client has a bad reaction to it.”

“To date, I have been denied 3 prescriptions for my son. Although I eventually received 2 of them, I had to borrow money to purchase one. The whole ordeal was stressful and humiliating!”

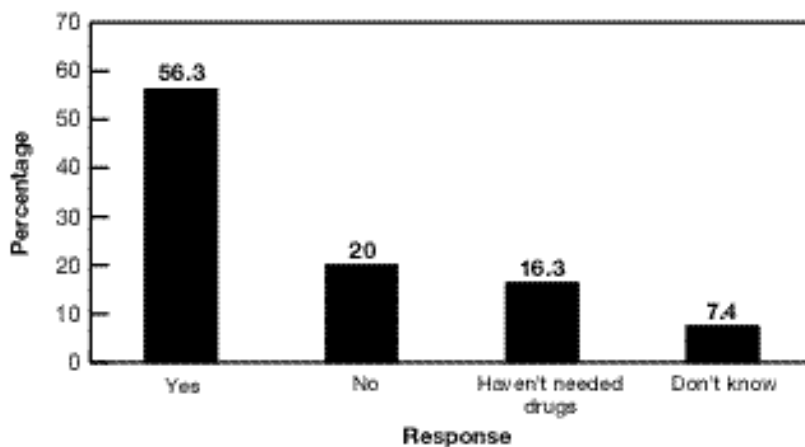
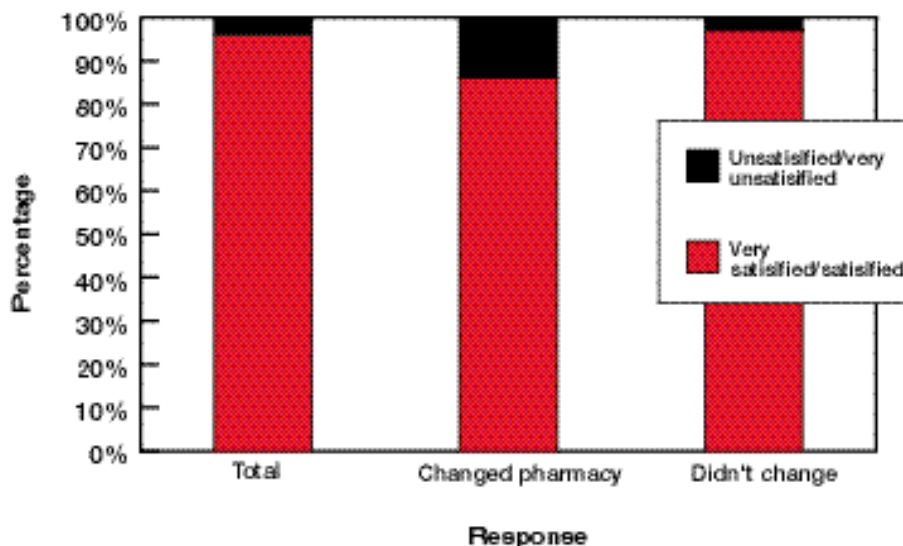
Accessibility

Over 90% of respondents were either very satisfied or satisfied with how easy it was for them to get in and out of provider offices and with how easy it was for them to use the examination tables or other equipment for medical tests (Figure 49).

General Satisfaction with HMO

We asked respondents to rate their satisfaction with their HMO and also invited them to tell us the best and worst aspects of their HMO. About 60% of respondents said that they were either very satisfied or satisfied with their HMO, while nearly a quarter said that they were either unsatisfied or very unsatisfied (Figure 50). The percentage of respondents who said

Figure 47. Rating of satisfaction with pharmacy (N=218).



they were very satisfied or satisfied with their HMO varied by plan; Horizon Mercy was highest (77.4%), followed by Health Net (74.2%), University Health Plan (65.5%), Amerigroup (52.8%), and AmeriChoice (45.8%). A difference in proportions test indicates that Horizon Mercy was significantly above average and AmeriChoice was significantly below average (p=.05).

To allow respondents to provide specific comments in addition to an overall rating, we asked two open-ended questions about the best and worst aspects of a respondent’s HMO. Responses to the questions ‘What is the best part of being in your HMO?’ (N = 210)

Figure 49. Rating of satisfaction with accessibility

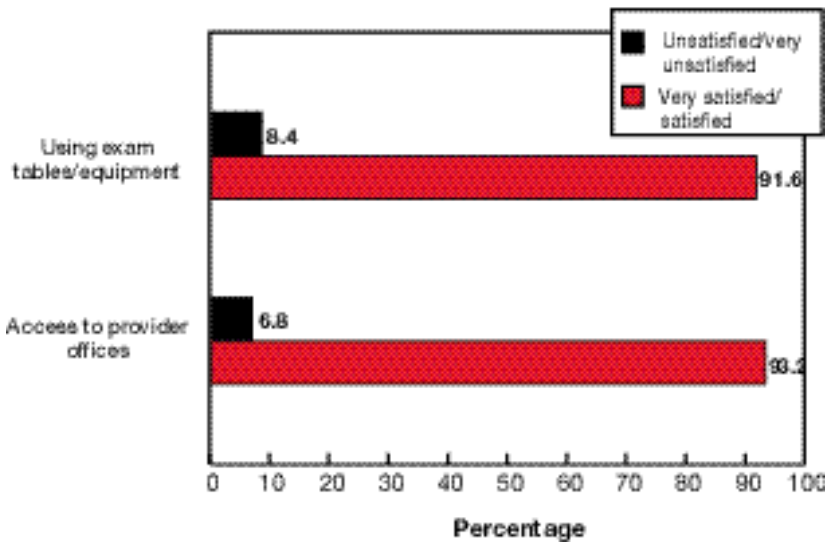
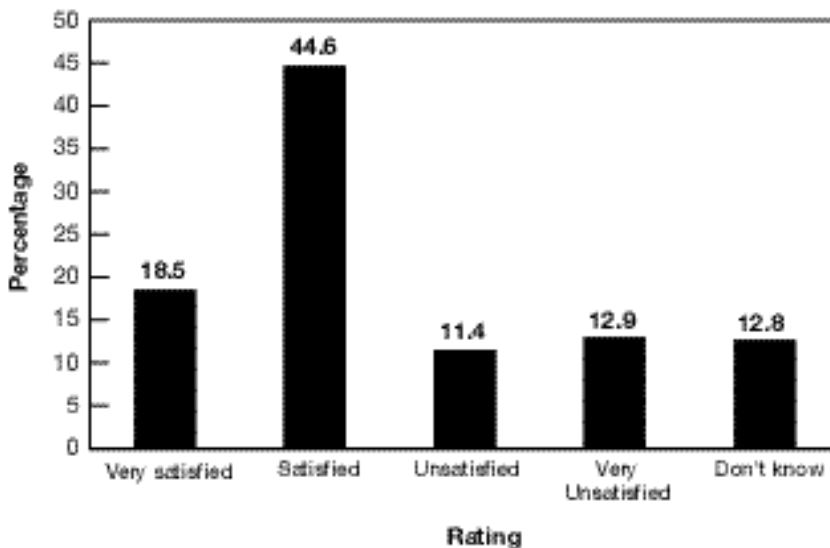


Figure 50. Rating of overall satisfaction with HMO (N=325).



and ‘What is the worst part of being in your HMO?’ (N = 224) provided a range of comments from quite negative to very positive. About half of the comments from respondents about the best part of being in their HMO cited the ability to keep the same primary care doctor, having a care manager, and the ability to keep the same specialists. A substantial number also mentioned having good doctors and getting better service or coverage than they had previously. Over half of the responses to the worst part of being in their HMO regarded the number of doctors, specialists and hospitals who do not accept coverage. Many of these

respondents mentioned that they had difficulty finding doctors, specialists, and dentists who accepted their HMO or who would accept new patients. The other most frequent negative responses were the difficulty and inconvenience of getting referrals and difficulties getting name brand medications.

Satisfied respondents had many positive comments regarding the best thing about their HMO. The following are representative of the most frequently-mentioned areas of satisfaction:

“The best part is I have a real good doctor.”

“We were able to continue medical care with our previous provider.”

“The primary care doctor is always available and you know you are covered.”

“Able to see my doctor and make appointments.”

“That (name) can still see her pediatrician since birth.”

“Able to keep the doctors my disabled child needs.”

“I’m very pleased with the plan. The primary care dr. and the other specialist was a member of that plan. The HMO plan never questions how often I need to see my doctors.”

“No out-of-pocket expense. Most specialists we see are members.”

“Having doctors that will see (name)—before doctors would not see him because of his disability—(fear).”

“I have better care with all doctors. I have better payments after care.”

“More choices in specialists.”

“It provides me with every service/no hassle.”

“Availability of services, i.e. speech, OT, counseling. However, would like to see bio feed back and other alternative health services offered.”

“Easy to reach them, and quick responses.”

“Feeling secure that my children are covered and attended to quickly.”

“Better doctor and to know that if I need help I can get it.”

“Care management with their monthly follow up.”

“The special care coordinator took care of finding and arranging for a pediatric dentist when the situation with our original provider was confirmed.”

“It provides help finding specialists fast and any other services, about the health.”

“One person, coordinator manager, to assist us directly.”

“Speaking to the managed care person.”

“Special needs coord. extremely helpful.”

“We have a case manager to turn to for advice.”

“I can call and get the information I need.”

“Horizon Mercy gives me satisfaction in everything; I need it.”

“They supply sufficient transportation and other services to accommodate me.”

The following are representative examples of the worst aspects of their HMO mentioned by respondents who were dissatisfied:

“The medication. The doctor prescribes something and the HMO won’t approve it—then I have to explain to the Dr. A big problem.”

“All the red tape you have to go thru in order to get service.”

“Every medication and test needed extra red tape to get them!”

“To get many referral forms and looking for specialist doctors. I am having trouble with service I had before; now I do not have.”

“Without a referral form you will not see your doctor.”

“Going to get referrals, have to call 3 places before I get an answer about any medical needs.”

“Example: Needing referrals now for x-ray. Dr. office using incorrect referral form—hospital turning me away resulting in extra trips and hassles for family members.”

“Referrals are difficult; my mother sometime takes off from work, to take me to the doctor or to get lab work and some places don’t take Horizon Mercy.”

“Doctors in our area are dropping out.”

“I call doctor after doctor; they have dropped out.”

“Lack of doctors/specialists participating in any of the Medicaid HMO. The doctors are bailing out as soon as their contracts are up with all of them.”

“Feel forced to change HMO for mental health and thus change PCP that treated for 20 years and truly knew history of patient. Documenting the need for certain prescriptions and having a lapse in the availability.”

“Most doctors are not in the plan, the ones that are far, the referrals (especially in emergencies) are a pain. They question meds 3-4 times. I left the pharmacy.”

“All the doctors and pharmacy we were using, no longer accept Horizon Mercy. I will have to change to another HMO because my son has autism w/speech.”

“Unable to find a dermatologist, surgeon or dentist in or near our area willing to accept it. At best they make you wait 3-4 months for an appt.”

Among the most negative responses:

“There is no good part. We have a very difficult time getting any type of medication.”

“There is no best part. It’s terrible!!!”

“I think HMO stinks.”

“I don’t like this program and I found it to be a horrible experience. I don’t have a disability. I can just imagine the difficulties my daughter would have encountered.”

Some respondents indicated negative reactions to the concept of managed care, rather than problems with an individual HMO. Some examples of these comments:

“I can’t go to any doctor that I wish.”

“Not being able to go to any doctor I need without checking to see if they belong.”

“Can’t be flexible to choose medically.”

“You can’t use it anywhere only where they accept it.”

“It takes time to research (parent needs to be informed in order to get the best doctor).”

“Restricted and limited compared to Medicaid.”

“The worst part about being in any HMO is how hospitals and drug stores can drop you.”

Awareness of Rights

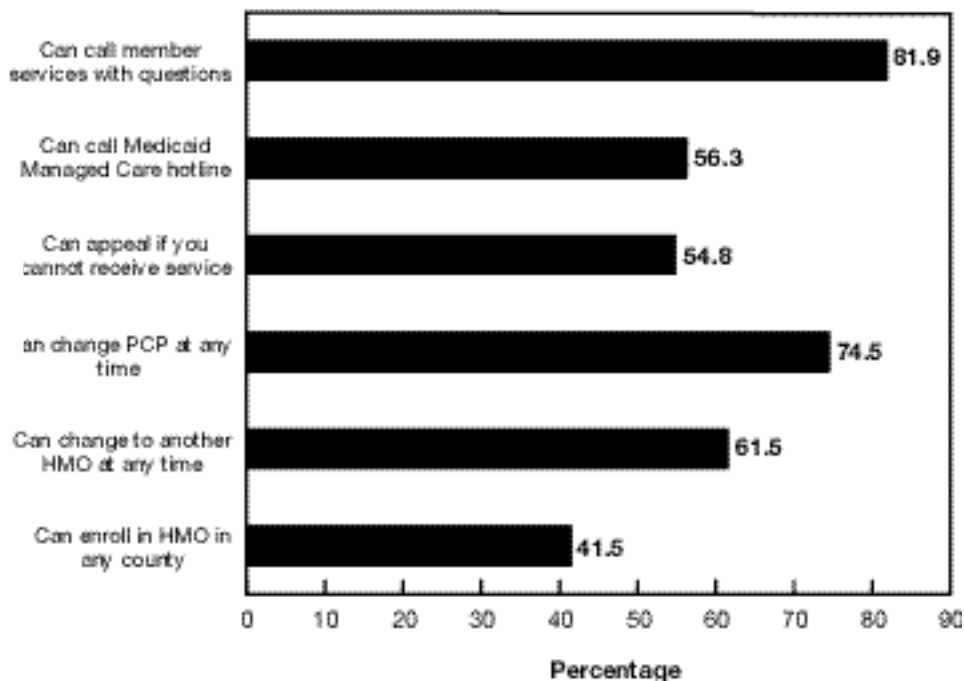
To insure that individuals can make informed choices and obtain the services to which they are entitled, it is important that they are aware of their rights. Near the end of the survey, we asked people about their awareness of their rights to enroll in an HMO in any county, to change their HMO or PCP at any time, to appeal denial of services, and to call members services at their HMO or the Medicaid Managed Care hotline. Figure 51 indicates the per-

centage of respondents who were aware of these rights.

The largest number of respondents were aware of the right to call member services with questions (81.9%) and change their PCP at any time (74.5%), but awareness of other rights was much lower. Participants in Horizon Mercy were significantly more likely than average to know that they had the right to change to another HMO or PCP at any time; participants in Health Net were also significantly more likely than average to know that they could change their PCP.

The next section discusses findings from the follow-up interviews.

Figure 51. Awareness of rights (N=325).



Results of Follow-up Interviews

During the second phase of the study, we interviewed 37 individuals who responded to the mail survey. The purpose of these interviews was to obtain more in-depth information about examples of difficulties people had experienced during enrollment and in receiving services from their HMO and the strategies they used to cope with these difficulties.

Respondents who were dissatisfied with their HMO commented on problems they experienced in the open-ended survey questions, but these brief comments provided little detail about whether problems occurred only once or repeatedly, what efforts had been made to resolve these problems, or whether problems had actually been resolved. The follow-up interviews were designed to provide more complete examples of the experiences which were associated with a negative reaction to managed care.

We chose respondents for follow-up from those who indicated a high degree of dissatisfaction with the enrollment/HMO selection process, those who indicated dissatisfaction with managed care, those who reported no contact with care managers, and those who indicated they had experienced difficulties. From responses to open-ended questions, we identified a group of parents (about 10% of respondents) who expressed extreme frustration at their inability to receive services, and a few of these were interviewed. We also attempted to balance the interviews between consumers, parents of young children, parents of adult children, and staff who had responded for consumers. Within these categories, we selected a number of individuals of Hispanic ethnicity. Sixteen of the consumers with completed follow-up interviews were female, six were Hispanic, and seven were black.

Semi-structured personal interviews were conducted with these 37 respondents to the mail survey to learn more about difficulties which these individuals had experienced and learn why their opinions of managed care were negative. A qualitative analysis of

the follow-up interviews yielded several different themes. These themes were repeated by several different respondents and they typically mirror comments written in by survey respondents. It should be noted that, as mentioned earlier, interviews were conducted specifically to focus on difficulties that survey respondents were having with the transition to managed care, and their strategies for dealing with those problems. Therefore, the themes that emerged from the interviews should not be viewed as representative of the experiences of all survey respondents. However, they identified examples of problems which were experienced by a significant minority of individuals who were dissatisfied with their HMO.

Two follow-up interviews were conducted directly with consumers, but most of the interviews were conducted with proxies, since nine of the consumers selected for follow-up were children and many of the others were not able to communicate personally with the interviewer. In two instances, we received some responses directly from the consumer, but other information was supplied by a staff person. Twenty-six of the proxy respondents were parents and ten were staff, either a group home manager or a medical liaison. All of the respondents knew the consumer well and were familiar with the person's medical care. Four of the interviews were completed in Spanish.

Enrollment/Selecting an HMO

Thirty-four respondents indicated on their mail survey that they had been assigned to a HMO even though they did not reside in Camden County. We

were interested to know why these people did not select an HMO. Eight of the parents we interviewed indicated that they felt they were forced to enroll in managed care and did not have a choice. They were told in letters and through phone calls that they had to sign up with an HMO or they would be assigned one. Most of these respondents said that they called an HBC and were assisted in choosing an HMO. However, a couple of respondents indicated that they just received their HMO card in the mail, and that they didn't recall completing an enrollment form.

Many parents interviewed appear not to have made an "informed" choice when choosing an HMO for their child. They often did not research the HMOs to see which one would suit their needs and had their current physicians in the HMO network. Some respondents indicated that they had difficulty figuring out the differences between HMOs and that they all seemed pretty much alike. These respondents usually relied on an HBC or someone else to tell them which HMO was "the best." One respondent from Camden County said that the enrollment form was too complicated to fill out, and she didn't have time to do it, so she was automatically assigned an HMO.

For seven out of the ten consumers living in group homes, the group home manager chose the HMO with approval from the consumer's parent or guardian. Staff from community providers appeared to feel more confident than families about selecting an HMO for the people they served, since the community providers had many opportunities to become educated about managed care and had 'experts' they could turn to within their own networks.

HMO Process/Paperwork

One of the main themes in dealing with managed care to come from the interviews was that of inconvenience. The process of having to get referrals, the length of time that referrals were good for, travel time to get to network doctors and having to go to network laboratories for tests rather than the local hospital were sources of inconvenience for 27 of the 37 respondents. Several of these respondents also noted that waiting times at network labs were longer than those at hospitals, and that the staff at network labs were not always trained to serve persons with developmental disabilities. One provider from a group home said that her

consumers have trouble waiting at the lab, and that waiting time is "horrible." A parent in Newark also complained that traveling to the lab and waiting for services was difficult for her and her adult daughter, because of the need to take time off from work and change busses to get to the lab, when she had previously used the local hospital for her daughter's monthly blood tests.

Eight of the respondents said that the referral process was inconvenient and time consuming, particularly for individuals who had to go to a lot of specialists or had to see the same specialist frequently. One parent reported having to go to her daughter's PCP's office every month to pick up referrals, and that this was difficult to do during office hours because she works during the day. Another parent had been trying to get a referral to an out of network pediatric diabetic specialist, and the HMO had "been giving her the run-around" for over five months, telling her that they were negotiating fees. She had also been waiting three months to see if the HMO would accept a low-vision specialist close to her home into their network.

The inconvenience of managed care was especially expressed by working parents caring for children with developmental disabilities. Several indicated that they had to take time off from work to take their children to see network providers that were not local or to go to physicians' offices during office hours to pick up referrals. One respondent noted that she frequently had to take her child out of school in order to travel to see a network physician. Another noted that she did not always feel safe in the neighborhoods where her child's new providers were located.

Several parents also indicated that gathering information or getting help on the phone was inconvenient. They had difficulty getting through to someone that could help them, and they sometimes still did not receive the help they needed. Several respondents said that, when they called for help, they were often transferred around to different people and were put on hold. It was not clear whether they were trying to call a HBC or their HMO. One parent said that she tried to call her daughter's HMO several times to ask about a claim that was denied but only got a recording or busy signal. Some parents we interviewed were confused about whom to call for information, especially for information about which physicians were in each

HMO's network and about changing HMOs. Fifteen of the respondents also said that filling out forms and paperwork was time consuming.

Paperwork was reported as a problem by three of the four Spanish-speaking respondents. Some also had problems getting interpreters when calling their HMO or HBC. One parent had someone call her about her son's HMO, but they did not speak Spanish so they couldn't help her. Some time later, she called her son's HMO and had to wait five minutes to speak to someone in Spanish. When visiting her son's new physician, her son had to translate for her because the doctor did not speak Spanish.

There was also confusion among respondents about what products and services HMOs covered, and getting payment for covered services was difficult for several respondents. For example, one parent said that she did not understand how HMOs work; she did not realize that some prescription drugs were not covered under her plan, and she spent an hour at a pharmacy trying to get a prescription filled that was denied by the HMO. She ended up paying for the drug out-of-pocket and had to borrow money to cover the cost. Six respondents, both parents and staff, indicated that they had trouble getting coverage for medications and durable medical goods such as diapers and leg braces. One parent had difficulty getting her son's HMO to approve payment for leg braces and a helmet for her son even after his PCP provided justification of the need for the products to the HMO. They told her that she had to get a note from an orthopedist, so she took her son to an orthopedist who wrote a note recommending the leg braces, but the HMO still didn't approve them. She called the HMO again and was told that the orthopedist had to call in the recommendation, not send it by mail or fax. So she had to call the orthopedist again and convey this information to him. This parent said that "this is not my only child and this is not my only problem! They give parents such a run-around and in the meantime the child is the one suffering!" (translated from Spanish).

Another parent could not get coverage for her daughter's nutrition supplement, diapers, or arm and thumb splints. She called the HMO and had her PCP write letters to the HMO explaining the medical necessity of the services, but they were still denied. Eventually, her daughter got dehydrated because she

wasn't getting her nutritional supplement and had to go to the emergency room. Because the hospital could not get approval from the HMO to admit the child for five hours, treatment was delayed and the child spent two days in the hospital. The parent was extremely frustrated because she felt that this was an issue that could have been easily resolved before it developed into a crisis.

Staff from community providers reported many of the same problems with paperwork as parents, although several had organizational support to assist them in coping. One medical liaison reported that the HMO which served several individuals for whom she had responsibility provided reimbursement for over-the-counter drugs. She had discovered this benefit by closely reading the handbook. However, she reported that she had spent substantial amounts of time working with pharmacies to make sure that they handled the paperwork correctly so that the HMO would pay for the medications. She observed that most parents probably overlooked this provision in the handbook and would not have the knowledge to negotiate with a pharmacy to receive this benefit for their child.

Primary Care Physicians and Specialists

Having to switch physicians was a source of enormous concern for 22 of the interview respondents. Several of these respondents said that they don't like to be told which physicians they had to use, especially when the new physicians do not know the case histories or complexities of the patients' health problems. One mother said that she had spent years finding providers to treat her daughter, and she had created a network of sensitive providers where information transfer was good between them, but enrolling in a HMO had forced her to get out of the network she had worked so hard to build for her daughter. Another parent said that she had problems with different physicians in the past because they didn't understand all of her son's health problems. Now that she had found someone that she felt understood his problems, she did not want to switch because she didn't want to "take a chance" with a new physician. Another parent even defined an HMO as "not being seen consistently by the same person."

Four of these respondents reported that, when their doctors tried to join an HMO network, they were

turned down and told that the HMO's network didn't need any more doctors in their specialty. Even when respondents were willing to switch doctors to see someone in their HMO's network, they reported problems with the availability of quality doctors with experience with developmental disabilities who were willing to accept payment from a Medicaid HMO. Three individuals reported selecting a new doctor and then were told that the doctor was not accepting any new patients.

Seven respondents had problems with their PCP dropping out of their HMO's network. This posed a major concern for these respondents since the PCP was often the doctor that the consumer had been seeing for a long time and with whom they had established a relationship. Similarly, other respondents had to choose new physicians when signing up for an HMO because the doctor they had been seeing did not accept payment from any of the Medicaid HMOs. After forming a relationship with a new physician, they were particularly frustrated when this doctor then dropped out of the network.

There was a feeling expressed by fourteen of the parents that the physicians in their HMO networks were substandard, and physicians who were good were not in their HMO's network. One parent said that the physicians in her son's HMO network were inferior, and another parent said that the network physician she takes her son to was not thorough enough. These parents often said they were not willing to change HMOs because, as one stated, "they're all the same."

Fourteen respondents had problems finding a network physician or dentist who was either familiar with the special needs of people with developmental disabilities or who was willing to treat someone with a developmental disability. Several parents commented that their new doctors did not understand the complex health problems that their children have – one parent said that the first new physician she took her daughter to after the change to managed care would not treat her because she was "too sick." Another parent reported problems finding a network dentist because her autistic son has to be physically restrained to receive dental care and "most dentists are not willing to go through that." One parent reported taking her daughter to a new gynecologist who was very impatient with her and made her uncomfortable. Then she

didn't want to go back.

Some of these respondents also said that both their previous physicians and any new physicians they wanted to go to refused to accept payment from a Medicaid HMO. One parent said that "doctors act like an HMO is a curse." One respondent said that her son's doctor "acted like he was doing them a favor" by seeing her son and the physician made it clear that he preferred private patients to Medicaid patients.

Care Managers

Interview respondents had little experience with care managers, but the six that did get in contact with a care manager found them to be very helpful in getting referrals and services. One parent said she had a difficult time getting in contact with her daughter's care manager. The care manager had called her but didn't leave a return number. When the parent called the HMO, they were not able to tell her the care manager's number. She eventually got the care manager's contact information from her daughter's pediatrician. The care manager took a medical assessment over the phone and was able to get her daughter all of the necessary referrals, and she has had a good experience in obtaining all services since then.

Community providers also said that they had difficulty getting care managers for the individuals they served. However, both parents and staff said that care managers were extremely helpful in finding specialists and obtaining additional services. Several mentioned that their negative attitude toward managed care changed after receiving care management. However, four respondents noted that turnover among care managers had been a problem; once a care manager left, it was difficult to find out who had taken over responsibility for coordination.

Problem Solving Strategies used by Interview Respondents

Twenty-eight of the 37 people we interviewed, particularly parents, were very frustrated with navigating the managed care system to get the care and services they felt that they needed. The first approach respondents tried when confronted with a problem was to call someone for help or information, usually either a HBC or their HMO. While this solved the problems for some respondents, several indicated that it had

been difficult to get accurate information or help from these sources, and that they sometimes had difficulty getting through to someone or received rude responses. A few respondents were given incorrect information over the phone, such as that they could not change HMOs.

As noted earlier, respondents described care managers as helpful in addressing consumers' problems, but there seemed to be too few care managers and they were not proactive in making contact with these consumers.

If calling an HBC or the HMO failed to get results, respondents sometimes called The ARC or other advocates for help. This approach was more often chosen by the providers we interviewed than by parents. Some parents seemed unaware that they could get help; others appeared to believe that it was useless to try to get help.

Nine of the parents that we spoke with got frustrated in dealing with managed care and either covered their child exclusively under one of the parent's policies or paid out of pocket for services. Many of these were paying out-of-pocket to take their child to the out-of-network providers they used before being enrolled in managed care. One respondent reported paying over \$7,000 out-of-pocket for wrist surgery for her daughter because the surgeon she wanted to use was not in her HMO. When asked if she knew that she could change her PCP or HMO, she responded that she had spoken with other parents, and they had told her that all Medicaid HMOs were the same, so she didn't think that changing HMOs would help.

Some of these respondents did not try to change doctors, get referrals to out-of-network physicians, or find some other way to get their child's care covered under their HMO. These parents often had talked with other parents who had trouble with the change to managed care, and they decided to not even try to navigate the system. Working parents in particular expressed the idea that trying to figure out managed care added another layer of complexity to their already complicated lives, and that paying out-of-pocket or switching coverage was an easier solution to the problem.

A few respondents indicated that their children were going without care because of problems navigating the system. One parent had not taken her son to a

dentist in over a year because his regular dentist did not accept his HMO, and the only local dentist that did accept it made him wait three months for an appointment and then canceled it and is not returning her phone calls. She called the HMO for help and their solution was for her to drive over an hour to take her son to another network dentist. Other respondents said they were not taking their children to see specialists because the ones they were used to seeing were not in their HMO's network, or because the network specialists they were assigned were located too far away from their homes. One parent said she had not been able to take her child to a pediatric dentist, diabetic specialist or a low-vision specialist because her HMO had not yet given her permission to take her daughter to out-of-network physicians, and the network specialists were over three hours from her home.

In general, we found that parents we interviewed were much less able to navigate managed care than were providers at group homes. The providers we spoke with had more access to resources to help them deal with problems than did parents, and providers knew of more avenues with which to address problems than did parents. Several staff mentioned that they had worked with medical staff in their own organizations to resolve issues. In some cases, they had brought the problems to the attention of officials at DMAHS, and the situation was resolved satisfactorily. As noted earlier, parents were more likely to get frustrated with the system, and they did not feel that they had the time to make all of the calls necessary to resolve problems, particularly when they had to make calls during work hours.

Summary and Discussion

The results of the mail survey for individuals recently enrolled in New Jersey Care 2000+ showed that overall 63% of respondents were satisfied with their HMO. Satisfaction varied by health plan; Horizon Mercy was significantly above average at 77.4%, and AmeriChoice was significantly below average at 45.8%.

Reasons for satisfaction mentioned by survey respondents included the ability to keep primary care physicians and specialists, having access to a full range of services, feeling that they were receiving a high quality of care, and assistance provided by care managers. Respondents were active in asking questions about their coverage; about half had called their HMO to ask questions.

The mail survey results indicated a very high level of satisfaction with Primary Care Physicians, both among individuals who kept their previous doctor and those who had changed. Over two-thirds of respondents were able to keep their previous doctor as PCP, and many were able to maintain their existing network of specialists. Over 90% of mail survey respondents were satisfied with all aspects of service from their PCP, including ability to get appointments, travel time, and accessibility. However, in written responses to open-ended survey questions and in follow-up personal interviews, some people expressed frustration over doctors dropping out of HMO networks and feared that there would not be enough high-quality physicians in their HMO network to meet their needs. This study did not assess whether doctors are actually leaving HMO networks, but that perception existed among some respondents who were dissatisfied with managed care.

Half of the mail survey respondents had been linked with a care manager, and those individuals who had care managers were extremely pleased with the services and credited their care managers for solving problems with access and expanding the services they were able to receive. Care managers provided substantial assistance with referrals and provision of new

services. Those respondents who received periodic follow-up from a care manager felt they were receiving tailored personal service, which they valued highly. However, other respondents reported that they had not been able to obtain a care manager, and a few people reported that services were interrupted when their care manager left.

The responses we received about the enrollment process were similar to those of other studies, which have noted that frustration with the enrollment process was substantially eased if up-to-date and comprehensive information about provider networks and providers with expertise in serving individuals with complex disabilities was available at the time of enrollment. About three-quarters of respondents to the mail survey found enrolling and selecting an HMO relatively easy. As in previous studies, we found that most people selected their HMO based on their ability to maintain relationships with existing providers.

Most respondents were assisted in enrolling and choosing their HMO by family members and guardians, with the rest getting help and advice from staff and medical professionals. In addition, Health Benefits Coordinators provided substantial information and assistance with enrollment. About half of the mail survey respondents had interacted with an HBC. Individuals who did not select an HMO or who had difficulty enrolling responded to open-ended questions about the selection process by noting that they found the paperwork confusing, that they didn't want to be in managed care and avoided selecting a plan, or that they had difficulty determining to which HMO networks their physicians belonged.

Most individuals were able to maintain their

network of specialists after joining an HMO. Others had developed a new network that met their needs, and half of respondents reported receiving new services. However, many of those respondents who were dissatisfied with managed care reported that they were unable to find dentists, gynecologists, and other specialists within a reasonable travel time who are skilled at serving individuals with disabilities. Over 90% of respondents were satisfied with the service from their Primary Care Provider regarding language and cultural issues. However, we found that in a few instances family members were acting as Spanish-language translators. This practice raises issues of both privacy and accuracy of the information transferred between an individual and his or her physician. The need for specialized providers who are experienced and knowledgeable about developmental disabilities and culturally competent is not unique to managed care, but these issues have increased the frustration of some participants in New Jersey Care 2000+ and their perception that managed care does not offer high quality care for people with disabilities.

Over 60% of respondents reported that they were generally satisfied with their HMO. However, there were substantial complaints among those who were dissatisfied about the inconvenience of getting referrals for services which were needed on an ongoing basis and difficulties getting approvals for brand-name prescriptions, medical supplies and equipment, and services which the doctor had deemed medically necessary. Because this study was conducted prior to the carve-out of prescription medications from the HMOs for SSI beneficiaries, we cannot provide any information about how this change in policy will address concerns about obtaining brand-name medications.

It was not clear from this study how often special needs assessments were completed and documented, since respondents were not always certain whether they had received an assessment. Forty percent of respondents reported receiving a special needs assessment, but others may have received one. It was not clear whether the HMOs have systems in place to insure that they have the necessary information to appropriately evaluate the needs of an individual with special health care needs.

We identified a group of parents (about 10% of the

sample) who appeared to have a great deal of difficulty understanding managed care and did not know where to get help. Follow-up interviews with a few of these parents confirmed their level of frustration. Despite all the efforts at outreach and education, these parents appeared to be overwhelmed with caring for their child, working, and trying to negotiate a system which they perceived as confusing and not designed to deliver high quality care. Many other respondents who experienced difficulties resolved them with help from a care manager, an advocate, or a doctor who intervened on their behalf. In contrast, these parents appeared unaware of the resources which might have helped them get the services they needed for their child and the rights which their children had under New Jersey Care 2000+. Even when they were aware, these individuals did not believe that it was worth trying to navigate the system. Some of these parents said that they were dropping out of managed care and paying for services privately, or they were forgoing services for their child. Additional outreach targeted to these parents would allow their children to receive the care coordination and additional services to which they are entitled.

Study Limitations

Readers should keep in mind several limitations while interpreting the findings of this study. The study was based on a sample survey, which has a statistical margin of error. Differences which are statistically significant are noted in the report. While the response rate was good for a mail survey, it is likely that non-respondents differ in important ways from respondents. After comparing guardianship and living arrangement data from the Division of Developmental Disabilities for respondents and non-respondents, we believe that parents were more likely to respond than DDD guardians or community providers. Also, since many surveys were completed by proxy respondents, it is possible that they do not accurately reflect the opinions of individuals with disabilities themselves. In addition, we received only ten responses from individuals who lived in Camden County and reported that they were automatically assigned to an HMO, so respondents are more representative of individuals who enroll voluntarily in managed care.

Endnotes

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2. Perry, M., & Robinson, N. (1999). *Individuals with Disabilities and Their Experiences with Medicaid Managed Care: Results from Focus Group Research*. Kaiser Commission on Medicaid and the Uninsured.
3. Long, S.K., Coughlin, T.A., & Kendall, S.J. (2002). “Access to care among disabled adults on Medicaid.” *Health Care Financing Review*, 23(4), 159-173.
4. Hunt, D., & Growick, B. (1997) “Managed care for people with disabilities.” *Journal of Rehabilitation*, 63(3), 10-15.
5. Regenstein, M., Schroer, C., & Meyer, J.A. (2000). *Medicaid Managed Care for Persons with Disabilities: A closer Look*. Washington, DC: The Economic and Social Research Institute.

Appendix A

Evaluation of New Jersey Care 2000+ Questionnaire

Evaluation of New Jersey Care 2000+

All information that could identify you or your family will be kept private. The Center for State Health Policy at Rutgers will not share your personal information with anyone without your permission. You may choose to answer the survey or not. If you choose not to answer, this will not affect the benefits you get in any way.

The following questions are about your Medicaid Managed Care HMO that is offered through New Jersey Care 2000+, and how you became a member of that HMO.

1. Which HMO are you enrolled in?

- | | |
|---|--|
| <input type="checkbox"/> Amerigroup
<input type="checkbox"/> AmeriChoice
<input type="checkbox"/> Horizon Mercy
<input type="checkbox"/> University Health Plans | <input type="checkbox"/> Health Net (formerly Physicians Health Services)
<input type="checkbox"/> No Longer Enrolled
<input type="checkbox"/> Don't know
<input type="checkbox"/> Not Answered |
|---|--|

2. Did you pick your HMO or were you assigned to one?

I picked it →

I picked Aetna, but was re-assigned to new HMO →

(answer questions #2 to #22a about Aetna, not your new HMO)

Q2 not answered - but response given in Q2a.

2a. Why did you select your HMO? Check all that apply.

- My doctor (Primary Care Provider) or specialist was a member of that plan
- Special or new services for children and adults with developmental disabilities
- Access to out-of-network specialists
- Transportation services
- Network includes out-of-state hospitals
- Other, specify: _____
- Not answered

(GO TO # 3)

I was assigned →

No Responses to Q2, Q2a, or Q2b (GO TO #3)

2b. Why did you choose NOT to select your HMO? Check all that apply.

- Enrollment form difficult to complete
- Never received enrollment form
- Never mailed in enrollment form
- Applied for an exemption
- Couldn't decide which one to pick
- Other, specify: _____
- Not answered

(GO TO # 3)

3. When did you become a member of this HMO? (Your best estimate is fine)

Month


- | | | |
|---------------------------------------|---------------------------------|-------------------------------------|
| <input type="checkbox"/> January | <input type="checkbox"/> May | <input type="checkbox"/> September |
| <input type="checkbox"/> February | <input type="checkbox"/> June | <input type="checkbox"/> October |
| <input type="checkbox"/> March | <input type="checkbox"/> July | <input type="checkbox"/> November |
| <input type="checkbox"/> April | <input type="checkbox"/> August | <input type="checkbox"/> December |
| <input type="checkbox"/> Not answered | | <input type="checkbox"/> Don't Know |

Year

- 2000
- 2001
- 2002
- Not answered
- Don't Know

You should have received an enrollment kit with a set of brochures and an application form in the mail from New Jersey Care 2000+ explaining how to enroll in Medicaid managed care. These questions are about the information in that enrollment kit.

4. Did you receive an enrollment kit in the mail?

- Yes 
- No (GO TO # 5)
- Not answered

4a. How easy was it to understand the information provided in the enrollment kit?

- Very easy Not answered
- Somewhat easy
- Somewhat difficult
- Very difficult

5. Did you or your family member attend an enrollment event?

- Yes No Not answered

6. How easy was it to select an HMO?

- Very easy Somewhat difficult Never tried to select one
- Somewhat easy Very difficult Not answered

7. Did anyone help you select your HMO? Check all that apply.

- Family member/guardian Other (nurse, doctor, social worker, etc.)
- Health Benefits Coordinator No one helped me
- Staff Did not try to select one
- Friend Not answered

8. Did anyone help you fill out the enrollment form? Check all that apply.

- Family member/guardian Other (nurse, doctor, social worker, etc.)
- Health Benefits Coordinator No one helped me
- Staff Did not try to select one
- Friend Not answered

9. How easy was it to understand where to get help with the enrollment process?

- Very easy Somewhat difficult Never tried to get help
- Somewhat easy Very difficult Not answered

10. Some individuals with complex medical or mental health problems may be eligible for an exemption from joining an HMO.

Did you apply for an exemption?

- Yes No Did not need to apply/Not Applicable
- Not answered Don't Know

The role of the Health Benefits Coordinators is to provide information and help with the enrollment process.

11. Did you speak with a Health Benefits Coordinator?

- Yes _____ →
- No (GO TO # 16)
- Not answered

11a. About how many times did you call before you spoke with a Health Benefits Coordinator?
_____ times
97 = Not answered
98 = Don't Know

12. When you called the Health Benefits Coordinator, did you have any difficulties (such as voice mail, having to transfer, waiting too long, etc.)?

- Yes
- No
- Not answered

13. Did you ask the Health Benefits Coordinator which HMO your doctors, specialists, pharmacy or hospital are in?

- Yes _____ →
- No (GO TO # 14)
- Not answered

13a. How helpful was the Health Benefits Coordinator about this?

- Very satisfied
- Satisfied
- Unsatisfied
- Very unsatisfied
- Not answered

14. Persons with both Medicaid and Medicare are not required to enroll in Medicaid managed care at this time. Do you have both Medicaid and Medicare?

- Yes _____ →
- No (GO TO # 15)
- Not answered

14a. Did you ask the Health Benefits Coordinator if you needed to enroll?
 Yes (GO TO # 14b)
 No (GO TO # 15)
 Not answered

14b. What was the Health Benefits Coordinator's response?
 Yes, you need to enroll (GO TO # 15)
 No, you did not need to enroll (GO TO # 15)
 Did not know (GO TO # 15)

15. Were you told any information that you later found out was incorrect?

- Yes _____ →
- No (GO TO # 16)
- Don't know (GO TO # 16)
- Not answered

15a. Please describe: _____

97=Not Answered

The following questions are about your experiences with your Medicaid HMO.

16. How did the HMO let you know that you were enrolled in their plan?

- | | |
|--|--|
| <input type="checkbox"/> I got a welcome call | <input type="checkbox"/> I called them |
| <input type="checkbox"/> I received confirmation in the mail | <input type="checkbox"/> I got welcome call & rec'd confirmation in mail |
| <input type="checkbox"/> The HMO never confirmed that I was enrolled in their plan | <input type="checkbox"/> Dr. rec'd confirmation |
| <input type="checkbox"/> Don't know | <input type="checkbox"/> Not answered |

17. Did you receive a member handbook from your HMO?

- Yes No Don't know Not answered

18. Did you call the HMO to ask questions?

- | | | |
|--|---|---|
| <input type="checkbox"/> Yes | → | 18a. How quickly did you reach the person you needed? |
| <input type="checkbox"/> No (GO TO # 19) | | <input type="checkbox"/> I did not have to wait |
| <input type="checkbox"/> Not answered | | <input type="checkbox"/> About 5 minutes |
| | | <input type="checkbox"/> About 10 minutes |
| | | <input type="checkbox"/> Over 10 minutes |
| | | <input type="checkbox"/> Not answered |

19. Did you have any problems receiving your ID cards?

- Yes, my HMO Card Yes, my Medicaid Card No Not answered

20. How would you rate your overall experience with enrolling in this new HMO?

Use any number from 1 (worst) to 5 (best).

- 1 (worst) 2 3 4 5 (best)
 Never received enrollment package Not answered Don't Know

Individuals with special needs are eligible to have a care manager at the HMO who makes sure they are referred to any special services needed and that the services are coordinated.

21. Were you linked with a care manager at your HMO?

- | | | |
|--|---|--|
| <input type="checkbox"/> Yes | → | 21a. How soon after you were enrolled were you linked with a care manager? |
| <input type="checkbox"/> No (GO TO # 22) | | <input type="checkbox"/> Less than 10 days |
| <input type="checkbox"/> Not answered | | <input type="checkbox"/> 10 to 30 days |
| <input type="checkbox"/> Don't Know | | <input type="checkbox"/> More than 30 days |
| | | <input type="checkbox"/> Not answered |
| | | <input type="checkbox"/> Don't Know |
| | | 21b. Has your care manager offered to help you get any health and medical services you need but your HMO does not cover? |
| | | <input type="checkbox"/> Yes |
| | | <input type="checkbox"/> No |
| | | <input type="checkbox"/> Haven't needed such services |
| | | <input type="checkbox"/> Not answered |
| | | <input type="checkbox"/> Don't Know |

The following questions are about your experience with other medical providers besides your Primary Care Provider since joining this HMO. Specialists are doctors like neurologists, orthopedists, allergy doctors, and skin doctors:

27. Were you able to keep your specialists when you joined the HMO?

- Yes, all of them
- Yes, some of them
- No, none of them
- Did not have any specialists previously
- Not answered
- Don't Know


28. Have you had any referrals to new medical or dental specialists since joining this HMO?

- Yes
- No
- Not answered
- Don't Know

29. Were you referred to any doctors outside your HMO network?

- Yes
- No
- Not answered
- Don't Know

30. Have you chosen a dentist since joining this HMO?

- Yes 
- No (GO TO # 31)
- Not answered

30a. How satisfied are you with your dentist?

- Very satisfied
- Satisfied
- Unsatisfied
- Very unsatisfied
- Have not seen yet
- Not answered

31. If needed, could you get the mental health or substance abuse services you wanted since joining this HMO?

- Yes
- No
- Don't know
- Not answered

32. If you needed crisis service since joining this HMO, did you get it?

- Yes
- No
- Haven't needed such services
- Not answered

33. Did you have to change the pharmacy where you usually go for prescriptions since joining this HMO?

- Yes
- No
- Not answered
- Don't know

34. Were you able to get brand-name drugs if required by your doctor?

- Yes
- No
- Haven't needed drugs yet

- Not answered
- Don't Know

	Very Satisfied	Satisfied	Unsatisfied	Very Unsatisfied	Not Applicable	Not ans./ DK
35a. How satisfied are you with how <u>quickly</u> you are able to get appointments with your Primary Care Provider (your main doctor)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35b. How satisfied are you with how quickly you are able to get an appointment with a specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35c. How satisfied are you with the time it takes to travel to see your Primary Care Provider?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35d. How satisfied are you with the time it takes to travel to see specialists?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35e. How easy is it for you to get in and out of provider offices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35f. How easy is it to use the examination tables or other equipment for medical tests, such as x-rays?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35g. If culture or language is an issue for you, how satisfied are you with the response of your doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35h. How satisfied are you with your new pharmacy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. Are you now receiving any services from your new HMO that you did not receive previously?

Yes 

- No
- Don't Know (GO TO # 37)
- Not answered

36a. Please specify which services you are now receiving from your HMO that you didn't receive before.

97=Not Answered

36b. How important are these services to you?

- Very important
- Quite important
- Not very important
- Not important at all

Not answered

37. What is the best part of being in your HMO? _____

97=Not Answered

98=Don't Know

99=Refused

38. What is the worst part of being in your HMO? _____

97=Not Answered

98=Don't Know

99=Refused

Are you aware of the following rights:	Yes, I am aware	No, I was not aware	Not Ans./ DK
39a. You may enroll in an HMO in any county in New Jersey, not just the one you live in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39b. You can change to another HMO at any time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39c. You can change your primary care provider at any time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39d. You may appeal if you cannot receive a particular service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39e. You may call the Medicaid Managed Care Hotline at 1-800-356-1561	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39f. You may call member services at your HMO if you have questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

These questions ask about yourself or the person you are helping complete this survey.

40. What is your age now?

_____ years old

97=Not Answered

41. Are you male or female?

Male

Female

Not answered

42. What county do you live in?

Atlantic

Essex

Monmouth

Sussex

Bergen

Gloucester

Morris

Union

Burlington

Hudson

Ocean

Warren

Camden

Hunterdon

Passaic

Not answered

Cape May

Mercer

Salem

Cumberland

Middlesex

Somerset

43. Are you of Hispanic or Latino origin or descent?

- Yes No Not answered

44. What is your race? Check all that apply.

- White
 Black
 Asian
 Native Hawaiian or other Pacific Islander
 American Indian or Alaska Native
 Other, please specify _____
 Hispanic/Latino/Dominican/Puerto Rican/Spanish/Mexican
 Not answered
 Don't Know

45. Did anyone help you fill out this survey? Check all that apply.

- Family member/guardian
 Non-family guardian
 Staff person
 Other, specify: _____
 No one helped me (SKIP TO Q.48)
 Not answered

46. How did that person help you? Check all that apply.

- Read the questions to me Not answered
 Wrote down the answers I gave
 Answered the questions for me
 Translated the questions into my language
 Helped in some other way (please specify): _____

47. How often do you see or talk on the phone with this person?

- almost daily
 at least weekly
 at least monthly
 about every 2-5 months
(3 or 4 times a year)
 about every 6-12 months
(once or twice a year)
 less often than once a year
- They live in my house/Daily/HH family member
 Pre-test version – Q47 not asked
 Not answered

48. If we follow up with people about the services they receive from their HMO, may we contact you?

- Yes
- Said "No," but still gave contact info.
- No
- Not answered

48a. Please provide your address and telephone number.

Address: _____

97 = Not Answered

Phone #: _____ - _____ - _____
97 = Not Answered

Thank you for your participation!

December, 2003

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