

PA DEVELOPMENTAL DISABILITIES COUNCIL

FINAL REPORT – NARRATIVE

Evaluating the HealthChoices Program: Pennsylvania’s Medical Assistance Program for Persons with Disabilities

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PROJECT DESCRIPTION

Overall Goals:

The overall goals of the project were to:

- Describe health care access and satisfaction of Pennsylvanians with disabilities who are covered through HealthChoices, the state’s managed care program for Medical Assistance recipients; and
- Recommend steps to improve health care for HealthChoices enrollees with disabilities based on the plan’s successes and problems identified during the project.

Focus group and survey methods were used to gather data from Pennsylvanians with physical and cognitive disabilities about their experiences, satisfaction, and difficulties with HealthChoices in three counties: Philadelphia, Lancaster, and Allegheny.

Background:

Most of the existing research on health care of persons with disabilities focuses on prevalence of primary and secondary conditions rather than issues of access, wellness/health maintenance, and impact of health policy. During the past few years, Pennsylvania has implemented significant changes in its health care delivery system for Medical Assistance recipients, but little is known about the impact of the program, positive or negative, on people with disabilities.

PROJECT ACTIVITIES

1. INFORMATION GATHERING

A. Methods

Focus groups were used in the first phase of the study to identify important positive and negative features of HealthChoices. Assistance with recruitment and hosting was obtained from numerous organizations. Participants included parents of children with disabilities, in groups held at Schreiber Pediatric Rehabilitation Center in Lancaster, Temple University in Philadelphia, and Achieva in Pittsburgh. Adults with physical disabilities participated in a fourth group at the Three Rivers Center for Independent Living in Pittsburgh. Soon after conclusion of the focus groups, adults dually eligible for Medicaid and Medicare, including 65,778 people from the three counties, were disenrolled from the program. While the State Bureau of Managed Care Operations was not able to identify the number with disabilities, the change clearly decreased the number eligible for the subsequent survey phase of the project.

A survey was then developed on enrollees' use of, satisfaction and difficulties with HealthChoices, after several existing surveys of similar content domains were reviewed. The project's survey reflected structure and content drawn from them, particularly the Consumer Assessment of Healthcare Providers and Systems (CAHPS) from the federal Agency for Healthcare Research and Quality (AHRQ); see Note 1 at the end of the report. The survey also reflected concerns highlighted during the focus groups. In addition to demographic information, the survey included the following domains: general plan administration, primary health care providers, specialists, access to care, office staff, communication, accommodations, prescription medicine, dental care, claims processing and grievances and complaints.

Seven disability advocacy organizations recruited participants by mailing a total of 4,580 letters inviting participation in the study. A return postcard was enclosed so that individuals could indicate whether they would like to participate and, if so, preference for mail, telephone or internet administration. The recruitment produced responses from 427 persons who identified themselves as eligible and interested in participating. Surveys were sent out by mail (313) or internet (73), or administered by phone (41). Of the total of 295 completed surveys, 101 could not be used because of clarification that the individual was not in fact enrolled in HealthChoices, missing demographic information, parents who responded to items on their own behalf rather than their disabled child, and respondents who reported mental health problems, rather than physical or cognitive disabilities. The remaining 194 surveys were the final data set.

In order to compare the HealthChoices data with information from persons without disabilities, CAHPS 2006 information for 1,634 adults on Medical Assistance from the three counties was obtained. Because the CAHPS survey did not include any information about disabilities, it was assumed that some unknown proportion of respondents were individuals with disabilities. Assuming that disability prevalence for CAHPS was consistent with overall figures for the Commonwealth of Pennsylvania, approximately 17% of the CAHPS data would represent persons with disabilities, compared to 100% of the project's HealthChoices data.

B. Results

Focus Groups

Excerpts from the verbatim transcripts are included in Section 5 of this report. Three themes were identified:

- Challenges focus group participants faced within the HealthChoices program, which included difficulty with obtaining timely approval of necessary care, finding providers willing to accept HealthChoices, and accessing reliable transportation to appointments.
- Concerns for the future of the program, which included participants' worries that possible changes in the HealthChoices program might result in increased cost or decreased access to care.
- Suggestions for improvement, which included increased communication and support from member services, greater uniformity among HealthChoices plans, and additional training for physicians and office staff focused on understanding disability and associated issues, including mental health.

The Institute Survey of Persons with Disabilities

Demographic information from the 194 respondents is tabled below. In general, respondents tended to be aged 45-64, women, White, with physical disabilities.

Characteristic	Level	N	%
Age	18 - 44	78	40.2
	45 to 64	106	54.6
	65 or older	10	5.2
Male gender		75	38.7
Race	Caucasian	123	63.4
	African American	64	33.0
	Other	7	3.6
Disability	Physical	136	70.1
	Cognitive	24	12.4
	Both physical and cognitive	34	17.5
County of Residence	Allegheny	80	41.2
	Lancaster	35	18.0
	Philadelphia	79	40.7
Enrolled in an additional health plan		58	29.9

Survey respondents appeared generally satisfied with the HealthChoices program. Most knew whom to call with questions about their plans (71.6%) and most reported that it was not very hard to find or receive information about their benefits (79.1%), and not hard at all to find a personal doctor or nurse (72.9%). The great majority (94.3%) had one person whom they considered their personal doctor or nurse. Most reported that it was not hard at all to get a referral (85.1%), although, with fewer reported it was not hard at all to find a specialist (67.1%), dentist (62.0%), or to obtain the care, tests, or treatment that they or their doctors believed necessary (63.6%). Most reported satisfaction with the treatment they received from specialists (77.9%) although fewer were satisfied with their dental care (67.3%). Most respondents (76.6%) reported they had not called or written to their health plans with a complaint or problem.

Although we had expected to examine differences based upon county of residence, county was confounded with ethnicity. The majority of respondents from Allegheny (76.3%) and Lancaster (94.3%) counties were White, whereas the majority of respondents from Philadelphia (66.7%) were non-White. We examined variations in access to and satisfaction with care depending on other demographic characteristics including age; kind of disability; whether or not the respondent belonged to a private health plan in addition to HealthChoices; and ethnicity. Not surprisingly, age was a factor in needed services: 76.5 % of respondents age 45 and older or their doctors had thought they needed to see a specialist during the previous year, compared to 62.3% of younger respondents. Although there were no differences in satisfaction by disability, there were expected differences regarding type of necessary equipment: 37.5% of those with cognitive disabilities needed durable medical equipment, compared to 79.0% of those with physical disabilities or both. Similarly, 25.0% of those with cognitive disabilities needed non-durable medical equipment, compared to 51.2% of those with physical disabilities or both.

Dental care

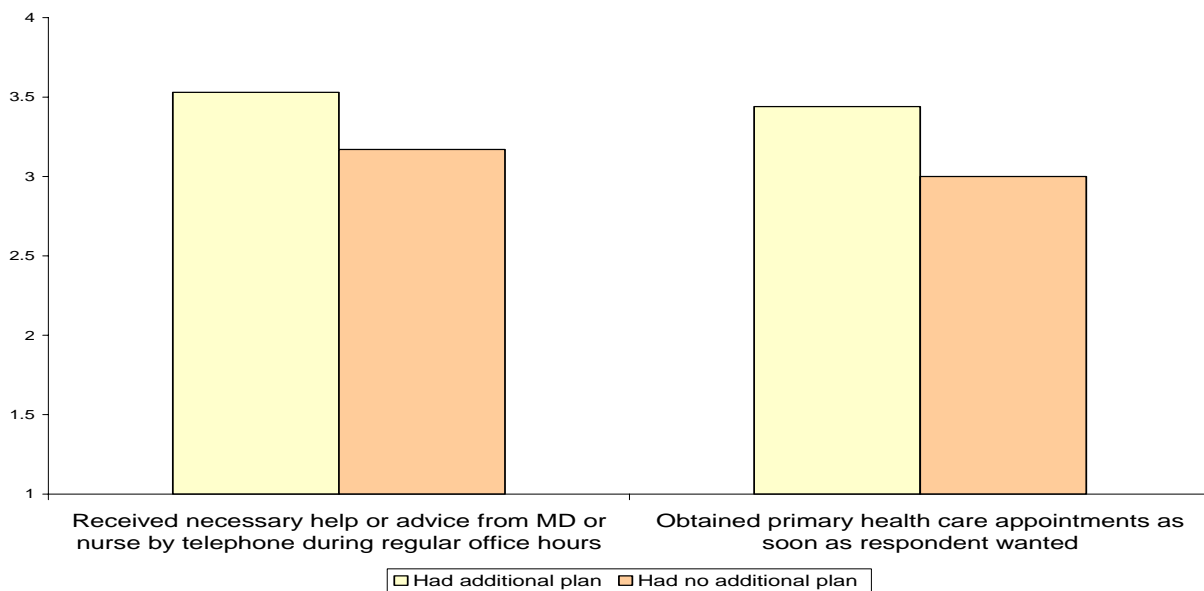
In the sample, 28% reported they didn't look for a dentist within the previous year. Of the 134 who did look for a dentist, 38% reported it was "very hard" to find a local dentist who accepted their health plan; 13% that it was "a little hard," and 49% that it was "not hard at all." Similarly, for the 135 respondents who reported they needed dental care within the previous year, 33% reported that it was "very hard" to get dental care in a timely manner. Overall, 67% responded "yes" to a question about whether they were satisfied with the dental care they received through their health plan.

Respondents with private coverage in addition to HealthChoices fared significantly better than those without such plans in referrals for non-routine care: 85% of respondents with additional health plans or their doctors believed additional care, tests, supplies, specialist care, or treatment in general had been needed during the previous year, compared to 66% of those without additional plans. This difference was consistent with the number of specialists seen during the previous year, which averaged 2.5 for those with additional coverage, compared to 1.5 for those without.

Respondents with additional coverage also reported they received needed telephone help and timely medical appointments from their primary care physician more frequently than those without, as shown in the graph on the next page (1=never; 2=sometimes; 3=often; 4=always).

Ethnicity was also important in access to and satisfaction with care. Four-fifths (79.5%) of White respondents or their doctors believed additional care, tests, supplies or treatment had been necessary, compared to 63.0% of non-White respondents. White respondents also reported going to the emergency room less often. Only 48.7% of White respondents had visited the emergency room during the previous year, compared to 62.5% of non-Whites. Of these respondents, 10% of Whites made more than three visits, compared to 20% of the non-White respondents.

Non-White respondents also reported higher levels of office staff who were never or only sometimes helpful (23.2%) compared with 10.3% of White respondents. Similarly, 15.9% of



non-White respondents said that office staff never or only sometimes treated them with respect, compared to 4.3% of White respondents.

Two-thirds (66.7%) of White respondents and 81.9% of non-White respondents reported they had a choice in selecting their health care plan. When asked who selected the health care plan, those who reported that they did not have a choice most often said that their parents or caregivers selected the plan for them. Others reported that their caseworkers or doctors chose their plan.

People with limited English proficiency:

In the HealthChoices sample, 62% said they spoke the same language as their health providers. Of the remaining 74 respondents:

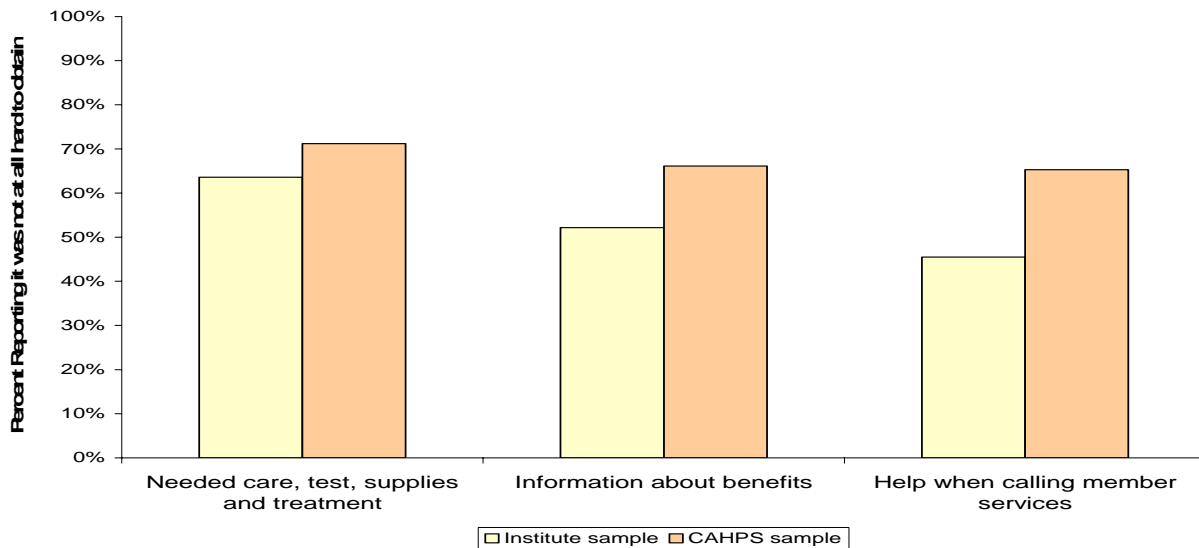
- 47 (24% of the entire sample) said they never had a hard time speaking with or understanding a doctor or other health providers because they spoke different languages;

- 18 (9%) said they sometimes had a hard time speaking with or understanding a doctor or other health providers because they spoke different languages;
- 3 (2%) said they usually had a hard time speaking with or understanding a doctor or other health providers because they spoke different languages; and
- 6 (3%) said they always had a hard time speaking with or understanding a doctor or other health providers because they spoke different languages.

The Institute Survey Compared to CAHPS Data

The data from the Institute’s HealthChoices survey were compared to information in the CAHPS database from a sample of Medicaid recipients who had not been selected for disabilities. Respondents to the Institute survey were more likely to report that there was one person who was their personal doctor or nurse (94.3%), and that the person was the same before and after selecting the health plan (84.2%), compared to CAHPS respondents (73.3% and 50.5% respectively). Compared to the CAHPS sample, HealthChoices respondents found it more difficult to obtain the care, tests, supplies or treatment that they or their doctor believed necessary, to find or get information about benefits, and to get needed help when calling member services, as shown in the graph on the next page.

There were no differences in office staff courteousness and helpfulness, respondent’s communication with the health provider, or whether appointments with the doctor or nurse could be obtained as soon as the respondent wanted. Satisfaction and experience with care providers did not differ across datasets. There was also no difference in whether the respondent had a choice in selecting or changing the health care plan, or in finding a doctor or nurse who accepted the plan.



2. NETWORKING ACTIVITIES

Members of the project's Advisory Board who assisted with development of the research instrument were adults with disabilities, including augmented communication users; parents of individuals with disabilities; and professionals who worked with persons with disabilities.

Focus group recruitment flyers were distributed to organizations across the three counties, including advocacy groups and a variety of service providers. Seven disability advocacy organizations agreed to recruit survey participants with disabilities in their counties by mailing a letter describing the study and a postcard to the members of their mailing list. The participating organizations were the Consumer Health Coalition and United Cerebral Palsy in Allegheny County; The ARC, United Disabilities, and the Disability Empowerment Center in Lancaster; and Vision for Equality and Liberty Resources in Philadelphia. After survey data were collected, AHRQ was contacted to request access to the CAHPS database. All members of the CAHPS Executive Research Committee approved granting access to the data.

3. INFORMATION DISSEMINATION

Two articles have been drafted and will be submitted for publication. The first reports results from the project's sample of participants. The second compares results from the project sample with the CAHPS 2006 Medical Assistance data for the general population not selected for disability. Final manuscripts will be sent to the DDC, and results will also be disseminated in consumer-friendly, accessible formats in print and on the web.

4. EVALUATION ACTIVITIES

The focus group protocol was evaluated and finalized with the assistance of the Advisory Board. The draft survey instrument was reviewed by the Board and staff at the Institute on Disabilities. After revision, the survey was piloted by a parent of a child with a disability and three individuals with disabilities for evaluation before deployment. As surveys were completed and returned, data were entered into a spreadsheet, cleaned and carefully evaluated for accuracy before analysis. The project team evaluated the CAHPS survey for items that could be appropriately compared with the project survey.

5. STORIES WHICH EMERGED, GENERAL DISCUSSION AND RECOMMENDATIONS

Although the surveyed Health Choices enrollees reported overall high satisfaction with their plans and lower, but still adequate, satisfaction with access to specialists and treatment, those with additional private coverage had better access to advice and timely care from their primary care providers than those without such coverage. They also fared significantly better in accessing specialized care. White respondents were more likely than non-White to indicate that they or their doctors believed additional care, tests, supplies or treatment were necessary, and less likely to say that medical office staff were never or only sometimes helpful and respectful. White respondents also reported going to the emergency room less often than non-White respondents. We do not know from these data if that was because the minority group tended to substitute the

emergency room for care through a clinic, as has been noted in other studies (Baker, Stevens, & Brook, 1994, Doty & Holmgren, 2006), or whether they were sicker and needed emergency treatment more frequently.

Several differences were found when the HealthChoices survey sample with disabilities was compared with the CAHPS respondents who had not been selected for disability. Respondents with disabilities found it more difficult to obtain the care, tests, supplies or treatment that they or their doctor believed necessary, to find or get information about benefits, and to get needed help when calling member services. On the positive side, the HealthChoices enrollees with disabilities were more likely to report that one person was their personal doctor or nurse, and that the person was the same before and after selecting the health plan. It is not clear why persons with disabilities reported higher rates than persons without disabilities. No differences were reported in office staff courteousness and helpfulness, respondent's communication with the health provider, whether appointments with the doctor or nurse could be obtained as soon as the respondent wanted, or satisfaction with primary care providers.

Although some of the information provided by individuals in the focus groups was consistent with that obtained from survey respondents, focus group participants tended to express less satisfaction with HealthChoices. There are several reasons why this may have occurred. First, the focus groups may have been influenced by the dynamics of the group. Second, those individuals who had a poor experience with the HealthChoices program may have been more motivated to attend a focus group session than individuals who were generally satisfied with their health care. Finally, the majority of focus group participants (87.5%) were parents of individuals with disabilities, whereas the majority of survey respondents (80.4%) completed the survey entirely on their own behalf.

The following comments by focus group participants have been transcribed verbatim:

“Doctors right now aren't trained to deal with people with disabilities. I would like to see a curriculum, course written up. There's probably a curriculum of having doctors learning how to deal specifically with the problems of people with disabilities. Because there are different problems that we have that quote-normal-people don't have, but doctors aren't trained for that, and it's up to the consumer to end up teaching them. It's something that they should already know, that they should learn in medical school. We shouldn't have to go in and teach them how to deal with us.”

“We had less trouble with Gateway partly because we use our gateway as a secondary insurance. We do have a primary insurance, but what I found was that over and over we needed a service; Gateway has come back and said denial... Blue Shield approved it. We then went back to Gateway and said, ‘uh, Blue Shield says this is medically necessary, what's the deal?’ ‘Oh, well, okay, yeah maybe you do need that.’ But really if it hadn't been for that, we had denial. We had many. We had less I think because it was secondary, but it concerns me how often we get denials from Gateway, saying this is not medically necessary, and then when they find out another insurance thinks it is, they turn around and say, ‘well yeah, okay, yeah, maybe you do need that after all.’ ”

“The other thing I guess that really concerns me about them too is that although this is considered part of the department of public welfare, this isn’t a welfare program. We are tax payers. The way we look at this is that this is our tax money actually being used to help us for a change. It’s not a handout where ‘here, we’ll give you money.’ And essentially what we’re being told is they can take our tax money from us, but they can’t use our own money to help us with our child. And that bothers me. I guess that’s a different way of looking at it, but I don’t look at it as a welfare program, it’s our money, and they’re saying no you can’t use it to help our kid, and it bothers me.”

“I mean, for me, in my case, I don’t have any other insurance, because I cannot work and I am a single mother. So I don’t have any other insurance, so I don’t have any other choice, and it’s not good. We are using it because we don’t have any other choice, and it’s the only way that I can get him doctors and hospitals and all that.”

“I just think it’s just a shame that, how much paperwork the doctors have to do. How can they concentrate on patient care, continuing education, learning these children, when they’re having to do letters of medical necessity every month for my, my 20 meds my daughter is on, her diapers, her enteral feeding formula, scripts for her oxygen and her apnea monitor.”

“They wasn’t really looking at me as a mother or a parent point of view, or at this child, ‘what is her problem?’ They were looking at it as money, or also wording. You know, if the doctor put some word, didn’t use the proper word, you know, as what they were saying. For instance, I got like 7 rejections in one week. And I’m like, ‘God what am I gonna do now? What am I gonna do now?’ What I was doing, appealing, appealing, and it was just returned, it was just redundant. Sending the same thing back to me over and over again, and it just got really frustrating.”

“The insurance company doesn’t feel that it’s necessary to pay for certain therapies because, you know, well, [children with disabilities are] the best that they’re going to be. Well no, if you continue with therapies, then the child will improve and then they’ll be productive members of society when they’re adults and hopefully won’t need as much health care, right?”

Recommendations for Improvement of the HealthChoices Program

The following general recommendations are based on results collected during the focus group and survey phases of the project:

An area for improvement identified by several focus group participants was **training of primary care physicians and office staff**. Inspection of the groups’ transcripts revealed a general feeling that the training should focus on understanding disability and associated issues, including mental health concerns. For example, routine examinations, such as weighing an individual, may need to be modified in order to accommodate patients with physical disabilities.

In survey results, patients with additional private plan coverage reported receiving more frequent necessary telephone consultation and timely medical appointments than did patients who relied on HealthChoices alone. Patients with additional coverage or their doctors were also 30% more likely to believe that additional care or treatment beyond primary practice were needed. Also,

minority patients reported decreased referrals to specialists and additional care; frustration at office staff's lack of helpfulness and respect; and use of the emergency room for care more often than White patients. Thus, care for minority patients with disabilities may be a particular area for improvement.

Focus group participants also recommended that the HealthChoices program **increase communication and provide additional assistance in navigating plan administration**. Parents suggested a monthly forum to keep them up to date and to apprise the health plans of their concerns, and/or a centralized location where they could obtain answers to questions. Some customer service representatives were seen as uninformed about plan coverage or reluctant to share information with plan members. Survey respondents with disabilities reinforced these complaints, reporting that information about benefits and assistance when calling member services was less available to them than reported by the non-disabled CAHPS sample.

Furthermore, focus group participants believed that the HealthChoices **administrative process could be improved by consolidation and streamlining**. For example, there was a suggestion that health care plans could keep a record of each child's medical history in some centralized computer system, particularly for foster children, so that treatments and tests weren't unnecessarily repeated. Additionally, there could be greater uniformity in coverage by the different providers under HealthChoices.

Finally, **a need for increased provider networks and timeliness of care approval** was noted by focus group participants. Survey results confirmed these findings: almost twice as many specialists were seen by patients covered with additional private insurance compared to Health Choices alone. Also, in the comparison of the disabled HealthChoices sample with the nondisabled CAHPS sample, disabled respondents found it more difficult to obtain the care, tests, supplies or treatment that they or their doctor believed necessary.

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Notes:

1. After August 15, 2007, contact Mary Segal, PhD, Research Scientist, Institute on Disabilities, with questions or comments about the project: segalm@temple.edu; 215-204-1978.
2. Sections in the report template on training, organizational development, outreach, and sustainability activities were not applicable to this research project.

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