

**A Survey of Functional Status  
to Support CommunityChoice Rate Setting  
and Program Assessments**

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## **Preface**

The Maryland Department of Health and Mental Hygiene, with initial funding from the Center for Health Care Strategies, has sponsored a sample survey to examine the distribution of, and extent to which, Maryland Medicaid recipients who are older adults or adults with disabilities report the need for support for basic activities of daily living (ADLs). The survey is intended as the first phase of a broader research agenda to explore how functional status as measured by ADLs is related to Medicaid resource use over time, as well as how such measures might be used for rate setting and performance assessment in the context of managed long-term care.

This report will focus on the development, conduct, and preliminary results of the survey itself. The following report sections include: a brief introduction of the context for this study; notes on the development of the survey and descriptions of the survey instrument and sample frame; notes on the conduct of the survey; selected preliminary survey results; and a summary of the survey process as a whole, including lessons learned. The final survey instrument with raw data results; background information on the survey center used to administer the survey; and the survey script introduction are included as attachments to this report.



## Introduction and Background

The Center for Health Program Development and Management (the Center) and the Maryland Department of Health and Mental Hygiene (DHMH) are exploring alternative approaches to set payment rates for Maryland's proposed managed long-term care program, CommunityChoice, as well as related issues regarding how to assess the program's population for administrative purposes over time. Under CommunityChoice, all Medicaid recipients who are also eligible for Medicare (dual eligible, or duals), Medicaid-only recipients 65 years of age and older, and Medicaid-only recipients between ages 21 and 65 deemed eligible for a nursing home level of care (NHLOC) will be enrolled in managed care plans (termed Community Care Organizations, or CCOs). CCOs will receive a prospectively set capitation fee to cover Medicaid-covered expenditures.<sup>1</sup> The services reflected in the capitation rate will primarily include institutional nursing home and community support services generally termed long-term care (LTC) under Medicaid but will also include Medicare co-payments and deductibles as well as acute care costs for enrollees who are not Medicare beneficiaries.

CommunityChoice is designed to facilitate better coordination of LTC services for Medicaid recipients as a whole with an emphasis on reducing unnecessary institutional care through a broader and more effective distribution of support services provided in the community. As in nearly every other state with a comparable program to date, consideration of a rate system for CommunityChoice has focused on a limited set of rate categories that generally reflect the site of care for LTC services that are provided to Medicaid recipients (e.g., institutional, community-dwelling NHLOC, and those with no formal NHLOC). At the same time, there is general agreement that categories based only on existing levels of care are not ideal to ensure fair and equitable payment for LTC services paid on a prospective basis or to influence desired provider behavior and outcomes, such as less dependency on institutional care, greater community integration, and improved health outcomes for community-dwelling individuals.

It is clear from discussions between DHMH and the Center that the initial rate system for CommunityChoice will need to be derived using existing data, which reflect current program assumptions. At the same time, the state has committed to examine more sophisticated methods for future use. To that end, the Center has been exploring what other methods might be put in place, such as those derived using diagnoses and/or measures of recipients' functional status. Diagnoses are commonly used as the basis for risk factors that underlie rate setting systems for acute care. However, more direct measures of functional status, such as a standard set of ADLs, are generally thought to be more appropriate as risk factors for the set of services defined as long-term care. Measures of functional status are already used in some form to help establish eligibility for nursing home level of care under Medicaid and in the determination of payment categories for skilled nursing care under Medicare, although research that examines their use to set Medicaid capitation rates is very limited.

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<sup>1</sup> Specialty mental health services are carved out of the CCO benefit package and provided through the Public Mental Health System.



A full examination of how and how well measures of functional status—and ADLs in particular—will work in the context of rate setting and program assessment for managed LTC under Maryland’s Medicaid program has been complicated by a lack of a consistent data, including associated costs, for the LTC-eligible Medicaid population as a whole. It was in this context that the Center proposed to conduct a sample survey to examine both operational aspects involved in using functional status to set payment rates for Medicaid LTC services and the extent to which such measures might help explain variation in service use and costs. Subsequent analyses also promise to shed light on how outcomes associated with program changes in service delivery are affected over time.

The survey described in this report is intended to:

- Establish and examine the distribution of ADLs within the CommunityChoice-eligible population as a whole to provide baseline measures for subsequent analyses, particularly for recipients with no formal NHLOC determination
- Collect information on the distribution of formal and informal community supports to, in part, improve the state’s assumptions about the extent to which Medicaid-covered services might be needed but are currently otherwise provided to the CommunityChoice-eligible population through other means
- Establish a study population (i.e., survey respondents) to track subsequent service use and fee-for-service costs in order to examine the relationship between those resource measures and functional status prior to the implementation of CommunityChoice
- Provide preliminary operational experience related to gathering measures of functional status in the context of CommunityChoice

Subsequent analyses will:

- Provide, in an understanding of the relationship between resource measures and functional status just noted, a context within which to examine changes in the distribution of resource use during the first year of CommunityChoice
- Evaluate the extent to which certain interventions or services, such as the introduction of a care coordinator for those who need support services, may delay or avoid loss of functional status or institutionalization
- Explore the relationships between ADLs, resource utilization, and informal supports that affect Medicaid program assumptions in more detail
- Provide preliminary operational experience on the use of functional status for rate setting purposes
- Begin to explore the link and interaction between Medicare and Medicaid service use and costs with respect to functional status in the context of emerging Special Needs Plans under the federal Medicare program



## A Survey of Functional Status Among a CommunityChoice-Eligible Population

The survey reported here was subject to several notable constraints. Timing was of particular importance because the larger study plan includes tracking relevant fee-for-service resource use of the respondent sample for at least one year prior to the implementation of CommunityChoice. When the survey was formally approved in early February 2006, DHMH was operating under the assumption that CommunityChoice would start as early as July 1, 2007. Thus, it was important to establish a respondent sample and collect initial survey data by the end of June 2006.

A preliminary sample size was set at 2,000 in order to ensure that the survey group would remain large enough over the subsequent year to effectively track resource use among various sub-groups of respondents. Consequently, costs were a constraint in that more intensive modes of collecting the survey data, particularly face-to-face interviews, proved to be too expensive given the available funds. Initial consideration was given to conduct a sub-sample of face-to-face interviews but, again, the cost, as well as the added time involved, proved prohibitive. Thus, the administration of the survey was limited to telephone contact. In addition, the survey was designed to be as short as possible to balance the amount of time any given respondent would need to answer questions with the level of detail on functional status and supports that was most important for analytical purposes.<sup>2</sup>

While the sample frame is discussed in more detail below, it is worth noting that consideration was also given to providing some form of written notice about the survey to potential respondents before the survey was conducted. In addition to the time and cost involved, however, the full sample frame was designed to include all possible eligible community-dwelling Medicaid recipients. This would have meant potentially raising unnecessary concerns among the entire eligible population when relatively few respondents would, in fact, be asked to participate. A special telephone number was provided during the survey so that respondents with un-allayed concerns could contact the study director with questions or comments.

By the end of February 2006, Institutional Review Board approval was received from DHMH and the University of Maryland, Baltimore County on an exempt basis and a subcontract with the Schaefer Center for Public Policy at the University of Baltimore to field the survey was established. A final survey questionnaire, a protocol to establish proxy respondents when needed, and a full telephone interview script were finalized by the end of March. Interviewing was completed between mid-April and mid-June 2006. The final development and administration of the survey—from the refinement of survey documents through the identification of an appropriate sampling frame and the conduct of the survey itself—was accomplished in a relatively short time period: between the end of February and the third week of June 2006.

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<sup>2</sup>It should also be noted that, while keenly aware that it will be needed, DHMH has not yet established a protocol to collect patient assessment data as part of the CommunityChoice enrollment process. This survey was designed as a modified version of the type of information that might be included in such an assessment. One benefit of this study is that it will provide some preliminary information about the feasibility and utility of relying on self-reported data collected in this way.



## The Survey Questionnaire

The core of the final survey questionnaire is a series of questions regarding the need for assistance to perform a standard set of ADLs consistent with those included in the Health Outcomes Survey (HOS) that the Centers for Medicare & Medicare Services (CMS) requires of Medicare Advantage plans. Survey respondents were asked if they need help with bathing, dressing, being fed, transferring from bed to chair, toileting, and general mobility in the home. In addition, respondents were asked if they get help preparing meals from friends, neighbors, or other agencies from outside the home. The basic information about activities that require support is used to provide counts of ADLs that underlie the functional status adjustment that CMS uses for Medicare capitation payment rates for some risk-bearing provider plans.<sup>3</sup> In addition to being asked if they need help with specific ADLs, respondents are asked the extent of difficulty they experience performing each activity, whether they have received help recently, and whether they have had trouble with specific ADLs because support was not available. A separate set of questions addresses the source of support (e.g., family, friends, or professional aides) for those who report receiving help.<sup>4</sup>

Detailed questions about specific medical conditions or the use of clinical or other support resources that might be used to characterize population differences related to functional status were not included in this survey not only to keep the survey short, but also because more complete and reliable claim information regarding those services is available to the Center through other sources. Thus, only limited additional information about service use and general health status was included in this survey. The survey questionnaire does include the SF-12 Health Survey,<sup>5</sup> which is a subset of the larger SF-36 Health Survey included in the HOS that CMS requires of all Medicare Advantage plans. The SF-12 was chosen because it is more limited than the SF-36 but still provides a nationally standardized measure of self-reported health status for the study population. Responses to the questions that make up the SF-12 are “scored” using weights provided with a license for the survey form and then summarized into two more broadly defined component measures of physical and mental health.

Attachment 1 includes a listing of the survey questions and raw data results for each question.

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<sup>3</sup>A function status adjustment, based on categories of counts of ADLs, is used to adjust capitation rates for Program for All Inclusive Care for the Elderly (PACE) plans, as well as special demonstration programs such as the Massachusetts Senior Care Options program, which links Medicaid and Medicare capitation payments to provider plans for dually eligible recipients enrolled on a voluntary basis.

<sup>4</sup>The questions regarding ADLs and attendant supports were drawn from a larger survey designed and conducted by Judith Kasper, Ph.D., for a study funded by the Robert Wood Johnson Foundation and the Commonwealth Fund. The study was reported in: Komisar, H., J. Feder, and J. Kasper, “Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles,” *Inquiry* 42: 171-182, Summer 2005; and Niefeld, M. and J.D. Kasper, “Access to Ambulatory Medical and Long-Term Care Services Among Elderly Medicare and Medicaid Beneficiaries: Organizational, Financial and Geographic Barriers,” *Medical Care Research and Review* 62: 300-319, 2005. Dr. Kasper served as a consultant to this project.

<sup>5</sup>Ware, J., et al., How to Score Version 2 of the SF-12 Health Survey (With a Supplement Documenting Version 1), QualityMetric Incorporated, Lincoln, Rhode Island, September 2005. Version 1 of the survey was used for the ADL survey.



## The Sampling Frame and Respondent Sample

The full sampling frame for this survey was defined to reflect all CommunityChoice-eligible recipients who reside in the community at any one point in time.<sup>6</sup> Within that larger frame, several key factors were considered to stratify a target respondent population in order to reflect underlying factors that might affect the results or impact subsequent analytical considerations. Those factors included nursing home level of care status, age categories, and geographic location. Age (divided into five categories) was chosen as the primary stratification criterion for sampling in order to stay within a target respondent population of roughly 2,000 and achieve a confidence level of at least 95 percent.

Five age categories (21-49; 50-64; 65-74; 75-84; 85+) were defined to broadly reflect some level of coverage status under existing Medicaid programs. The youngest group, ages 21 to 49, can be characterized as younger Supplemental Security Income recipients. The next group, ages 50 to 64, can be characterized as older SSI recipients who tend to exhibit medical conditions and service requirements in some respects more like younger “aged” Medicare recipients than the younger SSI group. Age 50 is also the lowest age eligible for the state’s Older Adult Waiver (OAW) 1915(c) waiver program. Fifty nine years of age is the cut-off for those eligible for the state’s Living at Home (LAH) 1915(c) waiver, so the 50 to 64 age group includes a mix of LAH and OAW waiver recipients. The remaining age categories split those who are 65 years and older, primarily Medicare beneficiaries, into somewhat arbitrary groups although, as just noted, the youngest “aged” Medicare group (ages 65 to 74) might be reasonably compared to the older SSI group in some respects.

Although it was not included in the power calculations used to establish the strata for sampling because the resultant sample size requirements would be too large, the sampling scheme also reflected recipients with a known NHLOC proportionately within each age category. NHLOC in the community was defined to include recipients enrolled in either the LAH or OAW programs at a reference point in time and recipients who had received medical day care or personal care<sup>7</sup> services as a Medicaid State Plan entitlement service within 30 days prior to that reference point in time.<sup>8</sup> The final sampling for the respondent population included ten cohorts that can be aggregated to examine results in at least three ways: across age categories, by NHLOC versus no formal NHLOC, and as a whole. The actual sampling frame for the survey was drawn in late February of this year with a reference date of December 1, 2005, in order to account for the lag in claims.

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<sup>6</sup>The roughly 23 percent of all recipients eligible for CommunityChoice who reside in nursing homes or chronic care hospitals are not included in the sample frame because there are significant other sources for data on their functional status, such as nursing home assessment data from the LTC Minimum Data Set, and because the primary focus of interest in this study is the community-dwelling population whose use of institutional services might be moderated through early attention to functional support need.

<sup>7</sup>Personal care in this instance is limited to personal care aides levels 2 and 3.

<sup>8</sup>In Maryland, individuals living in the community with an NHLOC may receive services from the LAH waiver, the OAW waiver, or medical day or personal care through the Medicaid State Plan.



For the first 2,000 responses, the Schaefer Center surveyed individuals at random from the actual sampling frame up to a set number for each of the ten cohorts to ensure that the distribution of the final responses was consistent with the population as a whole. Once the initial 2,000 responses were achieved, the sampling plan included up to an additional 100 responses. Since the power calculation used to set respondent targets only accounted for age categories, the NHLOC group was slightly over-sampled in the extra responses to help ensure that broad comparisons across the NHLOC and non-NHLOC groups would be statistically significant at the same level as that across age categories.

Table 1 shows the distribution of the CommunityChoice-eligible population living in the community, the actual sample frame, and the final respondent sample reported by the Schaefer Center. The leftmost column shows the full population as it would have been defined on January 1, 2006, by relevant sampling factors. January 1, 2006, was chosen as a point of reference in this table because the eligible population can now be tentatively defined using claims as of that date. Once more complete claims data are available for later months in 2006, the general reference date for the ongoing analyses of the survey respondent population will most likely be in June 2006, toward the end of the survey period.<sup>9</sup>

While more detail about the conduct of the survey itself is included in the next section, one significant administrative issue affected the identification of the actual sample frame. Telephone contact information for this survey was taken from existing Medicaid recipient information files. Close to 25 percent of the full sample frame did not have a telephone number listed in the Medicaid files. Perhaps because contact information for waiver recipients is generally more recent than for the population as a whole, those with phone numbers in the Center's Medicaid files included slightly more recipients with an NHLOC. Because the remaining population seemed to be large enough and the target respondent numbers would otherwise control for the distribution, only those who had a phone number in the Medicaid files were included in the actual sampling frame. The second column in Table 1 shows the distribution of the actual sampling frame that was submitted to the Schaefer Center for the survey. The distribution of the final survey respondent sample is shown in the rightmost column.

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<sup>9</sup>It will take 4 to 6 months after any given reference date to ensure enough time has elapsed to collect claims data relative to that point in time. This may affect overall eligibility for CommunityChoice, NHLOC status, and average costs reported in particular. Thus, distributions of those categories and measures included in this report may change somewhat, though not markedly, as more data relative to a later point in time (e.g., June as opposed to January 2006) become available.



Table 1: CommunityChoice-Eligible Population and ADL Survey Sampling Frame

		CC-Eligible Population as of 1/1/2006		Actual Sample Frame as of 12/1/2005		Final Respondent Sample as of 12/1/2005	
		persons	percent	persons	percent	persons	percent
1	Total Cmnty-Dwelling	47,243	100%	34,563	100%	2,090	100%
<i>Age Category</i>							
2	21-49	10,070	21.3%	6,981	20.2%	436	20.9%
3	50-64	6,493	13.7%	4,795	13.9%	425	20.3%
4	65-74	14,336	30.3%	11,013	31.9%	441	21.1%
5	75-84	11,752	24.9%	8,604	24.9%	442	21.1%
6	=> 85	4,592	9.7%	3,170	9.2%	346	16.6%
<i>NHLOC Status</i>							
7	NHLOC	6,582	13.9%	5,428	15.7%	386	18.5%
8	Other	40,661	86.1%	29,135	84.3%	1704	81.5%
<i>AgeCat. &amp; NHLOC Status</i>							
<i>21-49</i>							
9	NHLOC	616	6.1%	437	6.3%	39	8.9%
10	Other	9,454	93.9%	6,544	93.7%	397	91.1%
<i>50-64</i>							
11	NHLOC	850	13.1%	675	14.1%	69	16.2%
12	Other	5,643	86.9%	4,120	85.9%	356	83.8%
<i>65-74</i>							
13	NHLOC	1,480	10.3%	1,233	11.2%	56	12.7%
14	Other	12,856	89.7%	9,780	88.8%	385	87.3%
<i>75-84</i>							
15	NHLOC	2,284	19.4%	1,951	22.7%	92	20.8%
16	Other	9,468	80.6%	6,653	77.3%	350	79.2%
<i>=&gt; 85</i>							
17	NHLOC	1,352	29.4%	1,132	35.7%	130	37.6%
18	Other	3,240	70.6%	2,038	64.3%	216	62.4%

Note: 14,607 (23.1%) CC-eligible recipients were in a nursing home or chronic care hospital as of 1/1/2006.

It is worth noting, again, that the power calculations were made to ensure that results could be judged statistically significant across age cohorts. This, in effect, provides a kind of over-sampling in the 50 to 64 and 85 plus age groups. This was deemed useful in the case of the younger of those cohorts because, although relatively small, this group has been growing at a disproportionately fast rate in recent years. It proved to be particularly difficult to get the target number of respondents for the “Other” category of the oldest age group. While an initial target number of respondents was not achieved for this group, enough respondents were identified to ensure proportional representation for this group. This will be noted again in the following section on the conduct of the survey.



CommunityChoice is designed to include Medicaid-only recipients who otherwise meet the eligibility criteria for the program. Thus, one of the differences between the study population for this survey and that for the previous study noted earlier (see footnote 4) is that non-dual recipients are included in this survey. Although it is not emphasized in this report, non-dual Medicaid recipients make up 14 percent of both the full and actual sampling population for this study. That percent varies considerably by age from a low of 4.3 percent of those under 50 years of age to 24 percent of those who are 65 to 74 years of age. Slightly less than 10 percent of the final respondent sample is Medicaid-only, with a similar relative pattern across age categories. The final respondent sample size is large enough to ensure that duals can be meaningfully examined separately, but separate analyses of non-dual respondents will need to be more limited because of their small number.<sup>10</sup>

As noted earlier, once dependable eligibility and claims data become available, subsequent analyses of the survey respondent sample will use a reference date of June 2006 instead of January 2006 – the reference point in time for the full CommunityChoice population reflected in this report. While the impact of changes in the distribution of both the full and sample populations is likely to be very limited, some changes may occur. Those who are designated either NHLOC or “Other” in the respondent sample may have changed status by June. In addition, once the survey was complete, the primary survey respondent data file included 2,090 respondents. However, a small number of respondents (28) were found to have lost Medicaid eligibility or otherwise become ineligible for CommunityChoice as of January 2006. Those cases are not included in Tables 7 through 17 of this report but will be examined in more detail, along with other such cases that are identified in the coming months, and will eventually be included if deemed appropriate. Finally, data files for the survey included more than 75 partial responses that may provide additional response information for some questions. These are also not included in this report but will be examined in more detail over time and included as appropriate.

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<sup>10</sup>Most non-duals are enrolled in Maryland’s acute care managed care program known as HealthChoice.



## Conduct of the Survey

In March 2006, the Center entered into an agreement with the Schaefer Center for Public Policy at the University of Baltimore to administer the survey. Attachment 2 includes a brief description of the Schaefer Center survey facilities, staff, and survey management. The Schaefer Center's responsibilities included:

- Assisting with finalizing the survey instrument and the telephone script
- Programming the survey into the computer software (Ci3 Sawtooth) needed to perform a Computer-Assisted Telephone Interview (CATI)
- Conducting the actual telephone surveys through the CATI process
- Producing a data file in Microsoft Excel of all completed surveys
- Writing a methodology report

*Introductory Script and Proxy Responses.* An introductory script was completed in conjunction with the development of the computer-assisted protocols needed to field the survey. In addition to describing the purposes of the survey, this script included procedures to establish proxy respondents for those who could not respond on their own. Generally, when an initial phone response indicated that the recipient could not respond due to health reasons surveyors asked to speak with the most appropriate household member who had knowledge of the recipient's state of health and support needs.

Roughly 15 percent of responses were completed by proxy respondents. Each of the NHLOC cohorts had more than 20 percent proxy responses. Forty-six percent of the responses for the oldest NHLOC cohort (85 years of age and over) were completed by proxy. While the "Other" cohorts generally required fewer proxy responses, 24 percent of those recipients in the oldest age group responded by proxy.

It is also worth noting that, again because of the time and cost involved, no special effort (beyond asking for interpretation from household members when needed) was made to accommodate recipients who do not speak English. However, the study plan includes examining this group to the extent possible from available data. Attachment 3 is a copy of the script used to introduce the survey and establish proxy respondents when needed.

*Field Testing and Training.* A field test was run on April 24 to test the survey instrument as well as the computerized logic and data collection components of the Schaefer Center system. No significant adverse events or effects were identified. The testing made it possible to make initial estimates of the time involved to conduct each survey. On average, respondent time for the survey fell within the 20 minutes already estimated for the survey instrument and the full process of contacting and following up with respondents was well under an hour per survey. Data collection worked appropriately and data extracts could be exported in a suitable format.

In addition to the standard training described in Attachment 2, training specific to the ADL survey was also provided. This included the background and purpose of the survey as well as reminders and points specific to the survey as identified in the April 24 field test. Before



conducting any “live” surveys, all phone interviewers went through numerous practice runs to make sure they were completely familiar with the verbiage, text, and skip patterns of this particular survey. Only after a supervisor deemed that an interviewer was prepared was that interviewer allowed to begin to make live attempts to reach respondents.

*Survey Implementation.* Phone interviews occurred between April 26, 2006, and June 15, 2006, with 2,090 completed surveys distributed among the ten different cohorts (see Table 2). Over 34,500 individual dialing attempts were made to 18,876 individuals for these 2,090 completions. On average, completed interviews took just under fourteen minutes to complete.

*Sampling Frame.* The initial sampling frame provided to the Schaefer Center consisted of 34,563 potential survey respondents. The sample included a variable that identified each record as belonging to one of ten cohort groupings, described above, to ensure that the final set of completed survey data would be properly distributed across those groupings. The contract with the Schaefer Center was written to ensure an initial respondent sample of 2,000 with a caveat that the survey team would collect a limited number of additional responses if time and resources permitted. Table 2 reflects the cohort sampling scheme for the initial target of 2,000, requested numbers for additional responses, and the distribution of the final respondent sample.

Table 2: Sampling Frame Cohorts and Quotas

Cohort	Original Quota	Additional Quota	Final Completed Surveys
Total	2,000	100	2,090
<i>Ages 21-49</i>			
1 NHLOC	27	12	39
2 Other	377	8	397
<i>Ages 50-64</i>			
3 NHLOC	56	12	69
4 Other	339	8	356
<i>Ages 65-74</i>			
5 NHLOC	41	12	56
6 Other	368	8	385
<i>Ages 75-84</i>			
7 NHLOC	75	12	92
8 Other	332	8	350
<i>Ages 85 and above</i>			
9 NHLOC	118	12	130
10 Other	267	8	216

*Duplicate Telephone Numbers.* At the beginning of the actual survey process, the Survey Research Supervisor at the Schaefer Center identified a high proportion of “duplicate” phone numbers in the sample. These duplicates accounted for approximately 10 percent of the overall



sample. It was the opinion of the Survey Research Supervisor that these numbers should not be included as part of the sample. The duplicate numbers appeared to be randomly distributed, and the Survey Research Supervisor believed there would be no skewing or bias due to the elimination of these duplicate phone numbers. After consultation with the Center, the duplicates were set aside and not included in the initial sampling. That is, where duplicate telephone numbers were found among the sampling frame, only one individual per number was included in the telephone survey process. Some of these duplicates were eventually included in order to meet the sampling quota where needed.

In retrospect, despite some issues raised by problems encountered with cohort 10 (i.e., age 85 or older with no NHLOC) discussed below, it may have been better to include these cases in the survey from the start. On one hand, 50 percent of the duplicate numbers were associated with households that had two Medicaid recipients eligible for this study – presumably couples and two-member families who may provide each other important levels of support as well as small group settings. In general, excluding these individuals may be a (minor) lost opportunity to examine whether such households represent special cases of mutual support with implications for subsequent resource needs when one member of a household experiences a significant decline. It is unclear what direction the effect of excluding these individuals had on the overall results from this study, although further analysis of patterns of previous and subsequent resource use is possible if it is deemed appropriate. On the other hand, the remaining exclusions appear to be more generally associated with a single phone number for multiple residents in a group or assisted living setting. Assisted living providers, in particular, seemed to be less willing to facilitate participation in the survey than respondents who were contacted directly. While, as discussed above, prior written notice was not used for the full potential eligible population, targeted notices for group settings in particular may be helpful in the future. It also seems that some of the cases excluded in this context were individuals who had significant previous institutional care in a nursing home or chronic care hospital. The telephone number may have been entered into the Medicaid files during a previous institutional stay and not updated when the recipient left that setting. In any event, excluding these individuals may under-represent resource need reflected in the survey results to the extent that recipients with significant prior institutional care or residents of assisted living and other group homes tend to require such supports.

Cohort 10. It should be noted that it was not possible to fill the quota for cohort 10 given the time and resources available. In the third week of implementation, it became apparent that the response and cooperation rates for those identified as belonging to this group was far below the rates for the other nine cohorts. Upon investigation, the survey team found that:

- Many of the recipients identified in cohort 10 reside in assisted living facilities
  - Employees at many of these facilities refused to allow phone interviewers to talk to the respondent
  - In some cases where multiple calls were placed to a facility, phone interviewers were threatened with harassment charges



- This population had a much higher incidence of those who were unable to participate in the survey (physically/mentally)
- The numbers of records available in the sample for cohort 10 was not sufficient to overcome these challenges

Once the problem with cohort 10 was evident and the original quotas for most of the other nine cohorts were met, the Schaefer Center staff decided to: (1) open up the duplicate numbers associated with cohort 10 and (2) open up the other closed original quota cells in an effort to achieve the desired over-sampling requested by the Center.

At the end of May, the number of completions for cohort 10 stood at 146. After consultations with the Center, the Schaefer Center received contact information for an additional 1,200 recipients identified as cohort 10 sample but for whom there was no telephone number on file. Those data were cleaned and sent to an outside firm, Survey Sampling International, in an attempt to acquire phone numbers for the additional sample. Roughly 400 names were added to the sampling frame for cohort 10 as a result of this process.

*Final Survey Disposition by Cohort.* Table 3 includes a listing of categories that were used to track the disposition of survey contacts and respondents along with counts across those categories. The categories included in the table are based on standard definitions established by the American Association for Public Opinion Research (AAPOR). As with those who were excluded from the interview process because of duplicate phone numbers, future analysis based on other data sources will include examining differences between certain response disposition groups, the CommunityChoice population as a whole, and the survey respondent sample to estimate the level and direction of possible skewing of results that may be associated with those groups. For example, while an early decision was made not to provide translations of the survey, it would be useful for future purposes to examine whether the subgroup excluded based on a language barrier differs in meaningful ways from the population as a whole.

Tables 4a-c present some very preliminary indicators of the relationship between the overall (community-dwelling) CommunityChoice population as of January 1, 2006, and various groups defined by their final disposition within the sampling frame. In each of these tables, the distribution of the overall population across the primary study cohorts is shown in the leftmost column. Table 4a also includes comparable distributions for individuals who (1) were excluded because they refused to participate, (2) remained as a potential callback despite several attempts on the part of the survey team to follow-up, and (3) were excluded by default because of problems associated with phone numbers on file. Despite slightly higher percentages of NHLOC recipients that may be related in part to the higher percentage of those cases in the actual sampling frame shown in Table 1, above, these grouping do not seem to be markedly different in distribution from the population as a whole.

In addition to the information about the population as a whole, Table 4b includes columns that reflect those excluded because of language, a catch-all category of “Other,” and those in the actual sampling frame where no attempt to contact was made. The “Other” category, which



includes those found to be in a nursing home at the time of the survey and a higher percentage of the oldest cohort, and the “Not Tried” category are also reasonably comparable in distribution, with limited exception, to the overall population. The group excluded because of language is noticeably older and more likely to be designated NHLOC than the population as a whole.

Table 4c reflects the distribution of recipients in the initial actual sampling frame who were associated with duplicate phone numbers. This is before the duplicate numbers were “released” for those in cohort 10 and does not provide an indication of who among this group was actually included in the survey. At the same time, this shows that, as a group, these recipients were slightly older than the population as a whole and were slightly more likely to be designated NHLOC. Two-person groupings were markedly more likely to be between 65 and 84 years of age and, for those in the oldest age group, more likely to have an NHLOC.

Table 3: Final ADL Survey Disposition Distribution

AAPOR Final Disposition Code*	Category	Count
1.10	complete interview	2,090
1.20	partial complete	75
2.11	general callback	1,055
2.11	refusal	3,306
2.31	deceased	72
2.32	respondent unable to participate	139
2.33	language barrier	1,276
2.35	unable to complete (other)	80
3.12	busy	499
3.13	no answer	1,509
3.14	answering machine	2,256
3.90	other	462
4.20	fax/data line	29
4.32	not working/disconnected	3,180
4.41	wrong number	1,709
4.51	business/government	969
4.53	institution	124
4.70	not qualified	46
Total		18,876

\* Based on the American Association of Public Opinion Research standard definitions. See Attachment 2 for definitions and additional information on the calculation of response rates.



Table 4a: Disposition of Survey Sampling Population by Age Category and NHLOC Status

	CC-Eligible Population as of 1/1/2006		Refusals		Callbacks		Phone Problems	
	persons	percent	persons	percent	persons	percent	persons	percent
1	47,243	100%	3,306	100%	1,055	100%	10,150	100%
<i>Age Category</i>								
2	10,070	21.3%	567	17.2%	218	20.7%	2,939	29.0%
3	6,493	13.7%	390	11.8%	129	12.2%	1,717	16.9%
4	14,336	30.3%	707	21.4%	200	19.0%	1,826	18.0%
5	11,752	24.9%	845	25.6%	309	29.3%	2,261	22.3%
6	4,592	9.7%	797	24.1%	199	18.9%	1,407	13.9%
<i>NHLOC Status</i>								
7	6,582	13.9%	655	19.8%	171	16.2%	1,538	15.2%
8	40,661	86.1%	2,651	80.2%	884	83.8%	8,612	84.8%
<i>AgeCat. &amp; NHLOC Status</i>								
<i>21-49</i>								
9	616	6.1%	49	8.6%	20	9.2%	207	7.0%
10	9,454	93.9%	518	91.4%	198	90.8%	2,732	93.0%
<i>50-64</i>								
11	850	13.1%	55	14.1%	25	19.4%	253	14.7%
12	5,643	86.9%	335	85.9%	104	80.6%	1,464	85.3%
<i>65-74</i>								
13	1,480	10.3%	95	13.4%	37	18.5%	322	17.6%
14	12,856	89.7%	612	86.6%	163	81.5%	1,504	82.4%
<i>75-84</i>								
15	2,284	19.4%	234	27.7%	64	20.7%	450	19.9%
16	9,468	80.6%	611	72.3%	245	79.3%	1,811	80.1%
<i>=&gt; 85</i>								
17	1,352	29.4%	222	27.9%	25	12.6%	306	21.7%
18	3,240	70.6%	575	72.1%	174	87.4%	1,101	78.3%

Table 4b: Disposition of Survey Sampling Population by Age Category and NHLOC Status

	CC-Eligible Population as of 1/1/2006		Language		Other		Not Tried	
	persons	percent	persons	percent	persons	percent	persons	percent
1 Total	47,243	100%	1,276	100%	998	100%	16,938	100%
<i>Age Category</i>								
2 21-49	10,070	21.3%	41	3.2%	212	21.2%	2,724	16.1%
3 50-64	6,493	13.7%	37	2.9%	115	11.5%	2,107	12.4%
4 65-74	14,336	30.3%	311	24.4%	164	16.4%	7,567	44.7%
5 75-84	11,752	24.9%	503	39.4%	179	17.9%	4,252	25.1%
6 => 85	4,592	9.7%	384	30.1%	328	32.9%	288	1.7%
<i>NHLOC Status</i>								
7 NHLOC	6,582	13.9%	416	32.6%	181	18.1%	2,132	12.6%
8 Other	40,661	86.1%	860	67.4%	817	81.9%	14,806	87.4%
<i>AgeCat. &amp; NHLOC Status</i>								
<i>21-49</i>								
9 NHLOC	616	6.1%	6	14.6%	19	9.0%	103	3.8%
10 Other	9,454	93.9%	35	85.4%	193	91.0%	2,621	96.2%
<i>50-64</i>								
11 NHLOC	850	13.1%	10	27.0%	29	25.2%	240	11.4%
12 Other	5,643	86.9%	27	73.0%	86	74.8%	1,867	88.6%
<i>65-74</i>								
13 NHLOC	1,480	10.3%	73	23.5%	31	18.9%	628	8.3%
14 Other	12,856	89.7%	238	76.5%	133	81.1%	6,939	91.7%
<i>75-84</i>								
15 NHLOC	2,284	19.4%	188	37.4%	35	19.6%	897	21.1%
16 Other	9,468	80.6%	315	62.6%	144	80.4%	3,355	78.9%
<i>=&gt; 85</i>								
17 NHLOC	1,352	29.4%	139	36.2%	67	20.4%	264	91.7%
18 Other	3,240	70.6%	245	63.8%	261	79.6%	24	8.3%

Table 4c: Disposition of Survey Sampling Population by Age Category and NHLOC Status

	CC-Eligible Population as of 1/1/2006		All Dupe Phones		2 Persons		3 or More Persons	
	persons	percent	persons	percent	persons	percent	persons	percent
1 Total	47,243	100%	8,627	100%	4,390	100%	4,237	100%
<i>Age Category</i>								
2 21-49	10,070	21.3%	1,028	11.9%	348	7.9%	680	16.0%
3 50-64	6,493	13.7%	1,028	11.9%	250	5.7%	778	18.4%
4 65-74	14,336	30.3%	2,639	30.6%	1,857	42.3%	782	18.5%
5 75-84	11,752	24.9%	2,637	30.6%	1,557	35.5%	1,080	25.5%
6 => 85	4,592	9.7%	1,295	15.0%	378	8.6%	917	21.6%
<i>NHLOC Status</i>								
7 NHLOC	6,582	13.9%	1,637	19.0%	846	19.3%	791	18.7%
8 Other	40,661	86.1%	6,990	81.0%	3,544	80.7%	3,446	81.3%
<i>AgeCat. &amp; NHLOC Status</i>								
<i>21-49</i>								
9 NHLOC	616	6.1%	65	6.3%	25	7.2%	40	5.9%
10 Other	9,454	93.9%	963	93.7%	323	92.8%	640	94.1%
<i>50-64</i>								
11 NHLOC	850	13.1%	188	18.3%	54	21.6%	134	17.2%
12 Other	5,643	86.9%	840	81.7%	196	78.4%	644	82.8%
<i>65-74</i>								
13 NHLOC	1,480	10.3%	369	14.0%	215	11.6%	154	19.7%
14 Other	12,856	89.7%	2,270	86.0%	1,642	88.4%	628	80.3%
<i>75-84</i>								
15 NHLOC	2,284	19.4%	640	24.3%	386	24.8%	254	23.5%
16 Other	9,468	80.6%	1,997	75.7%	1,171	75.2%	826	76.5%
<i>=&gt; 85</i>								
17 NHLOC	1,352	29.4%	375	29.0%	166	43.9%	209	22.8%
18 Other	3,240	70.6%	920	71.0%	212	56.1%	708	77.2%

Table 5 shows the per-member-per-month (PMPM) Medicaid costs for calendar year 2005 by selected categories based on each recipient's final survey disposition. Costs are limited to those that are covered by CommunityChoice. The population as a whole accrued \$626 in costs PMPM on average. Recipients designated with an NHLOC cost \$2,054 and those with no NHLOC cost \$388 on average. Overall costs across disposition categories were reasonably comparable to those for the overall population with limited exceptions. All groupings had slightly higher PMPM costs for those designated NHLOC, particularly those with the catchall disposition designation of "Other." The total costs PMPM for "callbacks" were somewhat high, driven mostly by high NHLOC costs for the youngest age cohort and costs, generally, for the oldest age cohort. Total costs PMPM were higher for those excluded because of language, although the "Other" cohort of the youngest age category seems to account for much of this result. More detailed analysis is needed, but initial evidence indicates that the high PMPM of \$1,349 for this cohort is the results of one non-dual recipient with a history of high chronic care hospital costs among the 35 cases that comprise this group. This is also indicative of how these PMPM values can be influenced by high costs among relatively few cases. Overall, those excluded because of language were not markedly different in terms of costs than other groups.

Table 6 is comparable to Table 5 but reflects the population limited to cases where a given phone number was associated with more than one eligible recipient. As discussed above, in these cases only one individual per phone number was initially included in telephone sampling, although those in cohort 10 were eventually included. Average PMPM Medicaid costs for CY 2005 are shown for the total population of "duplicates" as well as separately for those cases where only two individuals were associated with a given telephone number versus where more than two individuals were associated with a number. As a whole, the group of recipients associated with duplicates had very high average costs, although those cases where only two individuals were included had average PMPM costs very similar to the population as a whole.

Cases where more than two individuals were associated with a given telephone number had markedly higher CY 2005 PMPM costs, particularly among those with no NHLOC. It is worth remembering that those not designated NHLOC as of the reference point in this report (January 1, 2006) were not enrolled in the LAH or OAW programs and had not received medical day care or personal care services in 30 days prior to the reference date. They were also not in a nursing home or chronic care hospital at the time of the survey or for the 30 consecutive days prior to the reference date. An initial review of available evidence suggests that this group—those who had phone numbers that were associated with more than two individuals—included a high number of recipients who received care in a nursing home or chronic care hospital earlier in 2005. Seventy cases among those in this group who were not designated NHLOC as of January 1, 2006, accrued more than \$80,000 in Medicaid costs during CY 2005. All of those cases were duals with some history of chronic care hospital and nursing home care. This suggests that overall results from this study may under-represent the total level of ADL support need among the CommunityChoice-eligible population to some extent because some individuals associated with duplicate telephone numbers were excluded from sampling.



Table 5: CY 2005 PMPM Medicaid Costs by Age Category, NHLOC Status, and Selected Disposition Groupings

	CC-Eligible Population as of 1/1/2006		Actual Sample Frame	Final Respondent Sample	Refusals	Callbacks	Phone Problem	Language		Other
		\$							\$	
1	Total	\$626	\$643	\$608	\$643	\$779	\$592	\$990	\$915	
<i>Age Category</i>										
2	21-49	\$486	\$507	\$453	\$507	\$633	\$428	\$1,453	\$518	
3	50-64	\$692	\$716	\$651	\$716	\$679	\$586	\$1,102	\$926	
4	65-74	\$479	\$481	\$489	\$481	\$587	\$589	\$665	\$811	
5	75-84	\$680	\$751	\$524	\$751	\$595	\$596	\$927	\$637	
6	=> 85	\$1,170	\$1,009	\$1,016	\$1,009	\$1,839	\$1,007	\$1,298	\$1,543	
<i>NHLOC Status</i>										
7	NHLOC	\$2,054	\$2,151	\$2,319	\$2,151	\$2,249	\$2,113	\$2,154	\$2,440	
8	Other	\$388	\$359	\$219	\$359	\$470	\$306	\$381	\$512	
<i>AgeCat. &amp; NHLOC Status</i>										
<i>21-49</i>										
9	NHLOC	\$2,273	\$2,452	\$2,634	\$2,452	\$3,133	\$2,269	\$1,996	\$2,947	
10	Other	\$365	\$372	\$234	\$372	\$367	\$284	\$1,349	\$264	
<i>50-64</i>										
11	NHLOC	\$2,258	\$2,384	\$2,498	\$2,384	\$2,324	\$2,275	\$2,493	\$2,340	
12	Other	\$452	\$435	\$295	\$435	\$274	\$289	\$559	\$402	
<i>65-74</i>										
13	NHLOC	\$1,932	\$1,990	\$2,128	\$1,990	\$1,964	\$2,037	\$1,874	\$2,591	
14	Other	\$305	\$281	\$236	\$281	\$271	\$261	\$266	\$351	
<i>75-84</i>										
15	NHLOC	\$1,955	\$2,047	\$1,950	\$2,047	\$1,987	\$1,995	\$2,106	\$2,116	
16	Other	\$364	\$345	\$154	\$345	\$230	\$232	\$192	\$240	
<i>=&gt; 85</i>										
17	NHLOC	\$2,126	\$2,250	\$2,470	\$2,250	\$2,536	\$2,127	\$2,356	\$2,438	
18	Other	\$751	\$513	\$138	\$513	\$1,685	\$628	\$607	\$1,190	

Table 6: CY 2005 PMPM Medicaid Costs by Age Category, NHLOC Status, and Phone Groupings

		CC-Eligible Population as of 1/1/2006	Actual Sample Frame	Final Respondent Sample	All Dupe Phones	2 Persons Per Phone	3 or More Persons Per Phone
1	Total	\$626	\$643	\$608	\$1,204	\$590	\$2,118
	<i>Age Category</i>						
2	21-49	\$486	\$507	\$453	\$1,275	\$496	\$1,732
3	50-64	\$692	\$716	\$651	\$1,611	\$703	\$1,969
4	65-74	\$479	\$481	\$489	\$787	\$413	\$2,056
5	75-84	\$680	\$751	\$524	\$1,163	\$661	\$2,351
6	=> 85	\$1,170	\$1,009	\$1,016	\$1,952	\$1,178	\$2,516
	<i>NHLOC Status</i>						
7	NHLOC	\$2,054	\$2,151	\$2,319	\$2,202	\$2,006	\$2,419
8	Other	\$388	\$359	\$219	\$909	\$235	\$2,007
	<i>AgeCat. &amp; NHLOC Status</i>						
	<i>21-49</i>						
9	NHLOC	\$2,273	\$2,452	\$2,634	\$2,502	\$1,960	\$2,843
10	Other	\$365	\$372	\$234	\$1,178	\$375	\$1,647
	<i>50-64</i>						
11	NHLOC	\$2,258	\$2,384	\$2,498	\$2,777	\$2,220	\$2,994
12	Other	\$452	\$435	\$295	\$1,285	\$285	\$1,681
	<i>65-74</i>						
13	NHLOC	\$1,932	\$1,990	\$2,128	\$2,108	\$1,857	\$2,464
14	Other	\$305	\$281	\$236	\$530	\$209	\$1,885
	<i>75-84</i>						
15	NHLOC	\$1,955	\$2,047	\$1,950	\$2,102	\$1,977	\$2,300
16	Other	\$364	\$345	\$154	\$773	\$208	\$2,383
	<i>=&gt; 85</i>						
17	NHLOC	\$2,126	\$2,250	\$2,470	\$2,122	\$2,217	\$2,041
18	Other	\$751	\$513	\$138	\$1,832	\$323	\$2,818

More detailed analysis that is beyond the scope of this report is needed to definitively establish what accounts for this result and to estimate the extent to which survey results are consequently skewed. At the same time, these results also indicate that the contact information available for this study was weak. The phone number on file for many of these cases may have been from an earlier time when these individuals were first enrolled under Medicaid and, at the same time, admitted in institutional settings. As more recent claims information becomes available, alternative approaches will be explored to categorizing individuals based on their actual status at the time of the survey and a longer view of previous resource use rather than the narrower (up to 30 day) point in time used for this report. For example, recipients who are not identified as NHLOC in this report might be categorized further to reflect a history of significant institutional care.



*Response Rate.* The Schaefer Center calculated response rates using AAPOR guidelines (see Attachment 2). Using the strictest of those standards and accounting for all aspects of failed attempts at contact, the overall response rate for this study is 16.3 percent. A calculation accounting for completed and partial surveys and refusals, including callbacks, would suggest a response rate of 33 percent. A standard refusal rate, including language barriers and various failures of telephone contact, is 34 percent. While seemingly poor on face value, these rates are not significantly different from other Schaefer Center surveys of this type, duration, and population. These response rates are preliminary and final response rates will be developed and reported with future analyses of the survey data. At the same time, preliminary analysis suggests that the final respondent sample reflects the underlying eligible population well and will suggest meaningful results over subsequent analyses.

## **Preliminary Results**

This section is intended to provide a cursory overview of the survey results as a whole and to highlight some initial questions raised by a preliminary array of those results that are likely to shape further analyses. Some of the survey's strengths and weaknesses will also be noted. Subsequent research to examine survey responses in more detail and to integrate other measures of service use and costs will provide more definitive analysis of specific issues.

The core questions in this survey ask whether respondents perform generally defined activities, such as bathing or transferring from bed to a chair, by themselves or with the help of others. All respondents were asked how difficult they would say any given activity is, whether they needed more help in the past month, and whether they had forgone the activity recently because they did not have the help they needed.

*Counts of ADLs.* Table 7 shows the number of ADLs for which respondents report receiving help (or that they do not perform the activity) by the primary grouping categories used to define the CommunityChoice population in this survey. Thirty-one percent of survey respondents report receiving help for one or more ADLs. More than 18 percent of respondents who currently receive some level of support services through LAH or OAW waiver programs, medical day care, or personal care (collectively termed NHLOC for this study) report no help for specific ADLs. On the surface, this result is curious in that those with an NHLOC designation are generally assumed to have need for functional supports. More analysis is needed to determine what other characteristics, such as skilled nursing care or other clinical support that is not otherwise associated with specific ADLs, might define the service needs of this population subgroup. At the same time, there may be some fault in the structure of the survey questions that does not pick up on existing need.

Some 5.9 percent of respondents who do not currently receive support services (termed "Other" for this study) report having help for three or more ADLs. Presumably, this group relies heavily on informal supports and other non-Medicaid sources for paid help. Because the underlying sampling scheme for this survey focused primarily on age categories, estimates of ADL support need for the population as a whole need to be weighted for the distribution of the larger



population. Adjusted for the age distribution of the population as a whole, 5.3 percent of those not now receiving support services through the Medicaid program report needing support for 3 or more ADLs. This percentage might be used to provide one very crude estimate of the extent to which those who do not currently receive support services may exhibit need under CommunityChoice and, thus, serve as a potential target for better coordinated care under the program. Based on the simple criterion of those who require help with three or more ADLs, these results suggest that approximately 2,100 individuals in the CommunityChoice-eligible population as a whole who do not currently receive support services might initially appear eligible for coordinated care services at some level. That would increase the current population who receive support services by roughly a third. It is very important to note how crude this estimate is. This estimate does not, for example, account for supports now provided on an informal and unpaid basis in the community. Subsequent analyses of the survey results will examine these issues from a variety of perspectives in much more detail.

As noted earlier, the core questions of this survey were largely drawn from a previous study (see footnote 4). While that previous study was limited to duals who were 65 years of age and older, this survey included: duals who were 21 and over; non-duals who were over 65; and, non-duals under 65 who require a nursing home level of care. Nevertheless, results on the distribution of ADL support need from this survey are closely comparable to those from the earlier study. Close to a third of both study respondents reported need for the help of another person for at least one ADL. One in seven respondents (14 percent) reported that they receive help for three or more ADLs in both surveys, although those who were 65 years of age or older in this survey reported slightly more need (approximately 16 percent, calculated from Table 7).



Table 7: Number of ADLs Where Respondents Have Help or Don't Perform (Percent of Respondents)

	Persons	ADL Counts (Percent of Row)						
		0	1	2	3	4	5	6
1	Total Cmnty-Dwelling 2,062	69.0%	11.0%	6.0%	3.9%	3.6%	3.3%	3.1%
2	<i>Age Category</i>							
3	21-49	76.3%	7.0%	4.4%	3.5%	3.5%	1.4%	3.7%
4	50-64	70.9%	13.0%	6.3%	2.9%	2.4%	3.1%	1.4%
5	65-74	80.5%	10.1%	2.5%	1.6%	3.4%	1.1%	0.7%
6	75-84	68.4%	13.0%	6.6%	5.5%	1.6%	3.4%	1.6%
	=> 85	43.7%	12.0%	11.4%	6.7%	8.2%	8.7%	9.3%
7	<i>NHLOC Status</i>							
8	NHLOC	18.3%	16.5%	15.4%	11.8%	12.0%	12.8%	13.1%
	Other	80.5%	9.7%	3.9%	2.1%	1.7%	1.2%	0.8%
9	<i>AgeCat. &amp; NHLOC Status</i>							
10	21-49 NHLOC	38	18.4%	5.3%	10.5%	13.2%	10.5%	7.9%
	Other	389	82.0%	7.2%	3.9%	2.6%	2.8%	0.8%
11	50-64 NHLOC	67	20.9%	23.9%	17.9%	7.5%	10.4%	9.0%
	Other	349	80.5%	10.9%	4.0%	2.0%	0.9%	0.0%
13	65-74 NHLOC	56	28.6%	26.8%	10.7%	8.9%	14.3%	3.6%
	Other	380	88.2%	7.6%	1.3%	0.5%	1.8%	0.3%
15	75-84 NHLOC	91	19.8%	22.0%	18.7%	16.5%	7.7%	4.4%
	Other	349	81.1%	10.6%	3.4%	2.6%	0.0%	0.9%
17	=> 85 NHLOC	130	11.5%	7.7%	15.4%	11.5%	15.4%	19.2%
	Other	213	63.4%	14.6%	8.9%	3.8%	3.8%	3.3%

*Those Who Report Receiving Help with ADLs.* Table 8 shows the percentages of all respondents reporting some level of (paid and/or unpaid) help for specific ADLs. The pattern of results overall is much the same across the two studies. In both studies, the need for help with bathing was most common, followed by dressing and transfer.<sup>11</sup> Problems with mobility were reported slightly less often, while toileting and feeding were reported more often in this study.

Table 8: Respondents Who Report Help for Specific ADLs or Don't Perform (Percent by NHLOC)

		Persons	ADL Help (Percent of Row)					
			bathing	dressing	feeding	transfer	toileting	mobility
1	Total	639	82.5%	59.3%	17.8%	44.4%	36.2%	33.0%
<i>Age Category</i>								
2	21-64	222	73.4%	56.8%	18.5%	49.5%	36.0%	27.9%
3	65 and Over	417	87.3%	60.7%	17.5%	41.7%	36.2%	35.7%
<i>NHLOC Status</i>								
4	NHLOC	312	93.9%	73.4%	24.0%	51.6%	49.0%	42.9%
5	Other	327	71.6%	45.9%	11.9%	37.6%	23.9%	23.5%
<i>AgeCat. &amp; NHLOC Status</i>								
<i>21-49</i>								
6	NHLOC	31	96.8%	83.9%	58.1%	64.5%	77.4%	51.6%
7	Other	70	61.4%	52.9%	18.6%	48.6%	31.4%	22.9%
<i>50-64</i>								
8	NHLOC	53	86.8%	67.9%	17.0%	45.3%	39.6%	34.0%
9	Other	68	64.7%	39.7%	1.5%	47.1%	19.1%	17.6%
<i>65-74</i>								
10	NHLOC	40	90.0%	60.0%	12.5%	35.0%	37.5%	30.0%
11	Other	45	66.7%	46.7%	4.4%	31.1%	20.0%	17.8%
<i>75-84</i>								
12	NHLOC	73	97.3%	60.3%	15.1%	38.4%	31.5%	32.9%
13	Other	66	78.8%	37.9%	9.1%	30.3%	18.2%	24.2%
<i>=&gt; 85</i>								
14	NHLOC	114	95.6%	86.0%	28.1%	65.8%	60.5%	55.3%
15	Other	51	80.4%	52.9%	15.7%	33.3%	27.5%	35.3%

Table 9 reflects the same population included in Table 8—those who report current help for specific ADLs—but for groups defined by the number of ADLs for which help is provided, as well as age and NHLOC status categories within those counts of ADLs. The need for assistance with transfer and toileting are consistently higher for those under 65 years of age who have help with fewer ADLs, which may help explain the generally higher percentages across those ADLs for this as opposed to the previous study.

<sup>11</sup>Results from Komisar, Feder, and Kasper 2005, which are most comparable to those in Row 3 of Table 3, are: bathing (85%); dressing (52%); feeding (13%); transfer (46%); toileting (23%); and mobility (42%).



Table 9: Respondents Who Report Help for Specific ADLs or Don't Perform (Percent by ADL)

	<b>ADL Count</b>	<b>Persons</b>	<b>ADL Counts (Percent of Row)</b>					
			<b>bathing</b>	<b>dressing</b>	<b>feeding</b>	<b>transfer</b>	<b>toileting</b>	<b>mobility</b>
1	1	226	60.2%	14.2%	2.7%	15.9%	2.7%	4.4%
2	2	124	90.3%	63.7%	5.6%	18.5%	9.7%	12.1%
3	3	81	91.4%	85.2%	11.1%	43.2%	35.8%	33.3%
4	4	75	96.0%	93.3%	10.7%	81.3%	74.7%	44.0%
5	5	69	100.0%	94.2%	29.0%	94.2%	92.8%	89.9%
6	6	64	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
<i>ADL Count &amp; Age Category</i>								
<i>1 ADL</i>								
7	Ages 21-64	84	46.4%	14.3%	2.4%	27.4%	4.8%	4.8%
8	65 and Over	142	68.3%	14.1%	2.8%	9.2%	1.4%	4.2%
<i>2 ADLs</i>								
9	Ages 21-64	45	82.2%	57.8%	6.7%	28.9%	13.3%	11.1%
10	65 and Over	79	94.9%	67.1%	5.1%	12.7%	7.6%	12.7%
<i>3 ADLs</i>								
11	Ages 21-64	27	85.2%	85.2%	14.8%	55.6%	40.7%	18.5%
12	65 and Over	54	94.4%	85.2%	9.3%	37.0%	33.3%	40.7%
<i>4 ADLs</i>								
13	Ages 21-64	25	92.0%	96.0%	20.0%	76.0%	80.0%	36.0%
14	65 and Over	50	98.0%	92.0%	6.0%	84.0%	72.0%	48.0%
<i>5 ADLs</i>								
15	Ages 21-64	19	100.0%	100.0%	26.3%	94.7%	89.5%	89.5%
16	65 and Over	50	100.0%	92.0%	30.0%	94.0%	94.0%	90.0%
<i>6 ADLs</i>								
17	Ages 21-64	22	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
18	65 and Over	42	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
<i>ADL Count &amp; NHLOC Status</i>								
<i>1 ADL</i>								
19	NHLOC	63	82.5%	9.5%	1.6%	4.8%	0.0%	1.6%
20	Other	163	51.5%	16.0%	3.1%	20.2%	3.7%	5.5%
<i>2 ADLs</i>								
21	NHLOC	59	93.2%	74.6%	3.4%	8.5%	8.5%	11.9%
22	Other	65	87.7%	53.8%	7.7%	27.7%	10.8%	12.3%
<i>3 ADLs</i>								
23	NHLOC	45	95.6%	86.7%	13.3%	35.6%	40.0%	28.9%
24	Other	36	86.1%	83.3%	8.3%	52.8%	30.6%	38.9%
<i>4 ADLs</i>								
25	NHLOC	46	95.7%	93.5%	8.7%	84.8%	76.1%	41.3%
26	Other	29	96.6%	93.1%	13.8%	75.9%	72.4%	48.3%
<i>5 ADLs</i>								
27	NHLOC	49	100.0%	95.9%	24.5%	98.0%	91.8%	89.8%
28	Other	20	100.0%	90.0%	40.0%	85.0%	95.0%	90.0%
<i>6 ADLs</i>								
29	NHLOC	50	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
30	Other	14	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%



*Levels of Difficulty and Frequency of Need.* Roughly comparable percentages of subgroups defined as receiving help with specific ADLs, as opposed to those who rely on themselves, reported that bathing, transfer, and mobility were somewhat difficult, while noticeably lower percentages of those with no help reported that dressing, toileting, and feeding were somewhat difficult (see Table 10). Among those with help, more than 54 percent reported that they found it very difficult to perform those tasks. Generally, 6 percent or less of those who reported no help found specific tasks very difficult. General patterns of the frequency of need are similar in that percentages of those with more limited need are roughly comparable across groups with and without help but percentages of those with frequent need are markedly higher for those who currently have help as opposed to those who do not. The number of respondents and associated percentages of those reporting a recent instance where they wanted to perform a specific ADL but could not due to lack of help are shown in the rightmost column of Table 10.

*Living Arrangements.* Results regarding living arrangements among respondents are shown in Tables 11 and 12 (12a and 12b). Table 11 shows results by two age categories and by NHLOC status across the five main age categories used in this study. Tables 12a and 12b show results by count of ADLs for which respondents receive help and by age categories and NHLOC status. Slightly less than 12 percent (11.7 percent) of all respondents (regardless of age) live with a spouse or partner. As one might expect, those over 65 are more likely to be living with their children (43.4 percent) and those under 65 are more likely to live with their parents (18.6 percent). Note that these are not mutually exclusive living arrangements except for those who live alone.

Almost 40 percent of survey respondents live alone. Although this is somewhat less than what was reported in the previous study noted earlier (53 percent, see footnote 4), one possible weakness of this survey is that there is no specific question about the type of residence. It is possible that some respondents who reported living alone have apartments or rooms in group settings such as assisted living facilities. At the same time, those who reported living with other non-relatives may also include those in assisted living arrangements. Knowing a little more about the nature of living arrangements might provide useful information about the full array of support services available to recipients and, by extension, need for additional support.



Table 10: Distribution of Level of Difficulty and Need by ADL

<u>ADL</u>		Persons	Somewhat Difficult	Very Difficult	Seldom or Occasional Need	Frequent Need	Recent Instance of Lack of Help
<i>Has Help or Does Not Do (Counts)</i>							
1	Bathing	527	167	317	91	379	155
2	Dressing	379	150	205	75	270	66
3	Feeding	114	27	70	11	81	12
4	Transfer	284	99	166	57	200	93
5	Toileting	231	73	126	25	164	56
6	Mobility	211	69	119	36	144	n/a
<i>Relys on Self (Counts)</i>							
7	Bathing	1,535	473	92	263	135	147
8	Dressing	1,683	444	58	275	114	82
9	Feeding	1,948	203	33	97	96	117
10	Transfer	1,778	566	81	281	111	163
11	Toileting	1,831	261	35	161	70	74
12	Mobility	1,851	565	80	334	144	n/a
<i>Has Help or Does Not Do (Counts)</i>							
1	Bathing	527	31.7%	60.2%	17.3%	71.9%	29.4%
2	Dressing	379	39.6%	54.1%	19.8%	71.2%	17.4%
3	Feeding	114	23.7%	61.4%	9.6%	71.1%	10.5%
4	Transfer	284	34.9%	58.5%	20.1%	70.4%	32.7%
5	Toileting	231	31.6%	54.5%	10.8%	71.0%	24.2%
6	Mobility	211	32.7%	56.4%	17.1%	68.2%	n/a
<i>Relys on Self (Counts)</i>							
7	Bathing	1,535	30.8%	6.0%	17.1%	8.8%	9.6%
8	Dressing	1,683	26.4%	3.4%	16.3%	6.8%	4.9%
9	Feeding	1,948	10.4%	1.7%	5.0%	4.9%	6.0%
10	Transfer	1,778	31.8%	4.6%	15.8%	6.2%	9.2%
11	Toileting	1,831	14.3%	1.9%	8.8%	3.8%	4.0%
12	Mobility	1,851	30.5%	4.3%	18.0%	7.8%	n/a



Table 11: Living Arrangements Among Respondents (Percent by Age Category & NHLOC)

		Living with...						
		Spouse or Partner	Children	Parent	Other Relative	Other Unrelated	Single or Unknown	
1	Total Cmnty-Dwelling	2,062	11.7%	35.5%	8.0%	23.1%	7.4%	39.4%
		<i>Age Category</i>						
4	21-64	843	11.7%	24.1%	18.6%	20.9%	9.5%	36.8%
5	65 and Over	1,219	11.7%	43.4%	0.6%	24.6%	6.0%	41.3%
		<i>NHLOC Status</i>						
	NHLOC	382	9.9%	33.0%	5.0%	23.8%	12.3%	37.2%
	Other	1,680	12.1%	36.1%	8.6%	22.9%	6.3%	39.9%
		<i>AgeCat. &amp; NHLOC Status</i>						
		<i>21-49</i>						
6	NHLOC	38	7.9%	5.3%	44.7%	15.8%	10.5%	34.2%
7	Other	389	11.8%	29.3%	28.3%	19.8%	11.1%	27.5%
		<i>50-64</i>						
8	NHLOC	67	13.4%	16.4%	1.5%	31.3%	14.9%	40.3%
9	Other	349	11.7%	21.8%	8.3%	20.6%	6.6%	46.7%
		<i>65-74</i>						
10	NHLOC	56	17.9%	32.1%	0.0%	14.3%	7.1%	48.2%
11	Other	380	14.5%	40.8%	1.3%	23.7%	4.5%	44.5%
		<i>75-84</i>						
12	NHLOC	91	7.7%	27.5%	0.0%	14.3%	11.0%	50.5%
13	Other	349	12.0%	42.4%	0.0%	23.8%	4.3%	44.1%
		<i>=&gt; 85</i>						
14	NHLOC	130	6.9%	53.8%	0.8%	33.1%	14.6%	22.3%
15	Other	213	9.4%	53.1%	0.5%	29.6%	3.8%	36.6%

Table 12a: Living Arrangement Among Respondents (Percent by ADL Count)

		Living with...						
		Spouse or Partner	Children	Parent	Other Relative	Other Unrelated	Single or Unknown	
1	ADL Count 0	1,423	11.7%	32.6%	8.4%	21.3%	6.2%	44.0%
2	1	226	11.1%	39.8%	4.0%	26.1%	8.0%	35.4%
3	2	124	5.6%	38.7%	8.9%	24.2%	12.1%	33.9%
4	3	81	9.9%	38.3%	6.2%	28.4%	21.0%	24.7%
5	4	75	18.7%	46.7%	9.3%	34.7%	9.3%	21.3%
6	5	69	15.9%	46.4%	5.8%	24.6%	5.8%	20.3%
7	6	64	15.6%	50.0%	12.5%	28.1%	6.3%	23.4%



Table 12b: Living Arrangement Among Respondents (Percent by ADL Count)

ADL Count	Persons	Living with...						
		Spouse or Partner	Children	Parent	Other Relative	Other Unrelated	Single or Unknown	
<i>ADL Count &amp; Age Category</i>								
<i>0 ADLs</i>								
8	Ages 21-64	621	11.3%	24.6%	18.2%	20.1%	8.9%	38.3%
9	65 and Over	802	12.1%	38.8%	0.9%	22.2%	4.1%	48.4%
<i>1 ADL</i>								
10	Ages 21-64	84	9.5%	26.2%	10.7%	29.8%	11.9%	36.9%
11	65 and Over	142	12.0%	47.9%	0.0%	23.9%	5.6%	34.5%
<i>2 ADLs</i>								
12	Ages 21-64	45	8.9%	15.6%	24.4%	11.1%	11.1%	35.6%
13	65 and Over	79	3.8%	51.9%	0.0%	31.6%	12.7%	32.9%
<i>3 ADLs</i>								
14	Ages 21-64	27	11.1%	29.6%	18.5%	14.8%	18.5%	29.6%
15	65 and Over	54	9.3%	42.6%	0.0%	35.2%	22.2%	22.2%
<i>4 ADLs</i>								
16	Ages 21-64	25	16.0%	20.0%	28.0%	32.0%	8.0%	28.0%
17	65 and Over	50	20.0%	60.0%	0.0%	36.0%	10.0%	18.0%
<i>5 ADLs</i>								
18	Ages 21-64	19	26.3%	21.1%	21.1%	21.1%	0.0%	26.3%
19	65 and Over	50	12.0%	56.0%	0.0%	26.0%	8.0%	18.0%
<i>6 ADLs</i>								
20	Ages 21-64	22	22.7%	18.2%	36.4%	22.7%	13.6%	22.7%
21	65 and Over	42	11.9%	66.7%	0.0%	31.0%	2.4%	23.8%
<i>ADL Count &amp; NHLOC Status</i>								
<i>0 ADLs</i>								
22	NHLOC	70	4.3%	21.4%	5.7%	20.0%	8.6%	58.6%
23	Other	1,353	12.1%	33.2%	8.6%	21.4%	6.1%	43.2%
<i>1 ADL</i>								
24	NHLOC	63	12.7%	17.5%	0.0%	12.7%	17.5%	49.2%
25	Other	163	10.4%	48.5%	5.5%	31.3%	4.3%	30.1%
<i>2 ADLs</i>								
26	NHLOC	59	3.4%	28.8%	3.4%	28.8%	15.3%	40.7%
27	Other	65	7.7%	47.7%	13.8%	20.0%	9.2%	27.7%
<i>3 ADLs</i>								
28	NHLOC	45	11.1%	22.2%	6.7%	24.4%	22.2%	31.1%
29	Other	36	8.3%	58.3%	5.6%	33.3%	19.4%	16.7%
<i>4 ADLs</i>								
30	NHLOC	46	13.0%	50.0%	6.5%	32.6%	8.7%	26.1%
31	Other	29	27.6%	41.4%	13.8%	37.9%	10.3%	13.8%
<i>5 ADLs</i>								
32	NHLOC	49	14.3%	49.0%	2.0%	26.5%	8.2%	18.4%
33	Other	20	20.0%	40.0%	15.0%	20.0%	0.0%	25.0%
<i>6 ADLs</i>								
34	NHLOC	50	14.0%	52.0%	12.0%	26.0%	6.0%	22.0%
35	Other	14	21.4%	42.9%	14.3%	35.7%	7.1%	28.6%



*Source of Help and Satisfaction with Help.* In addition to the core questions about help for specific ADLs, respondents were asked several questions regarding the nature of their community supports and the extent of help they received recently. Respondents were asked about specific categories of family, friends, and professional aides, as well as how many hours in a typical day and days in a typical week that support was available. Help from family and friends can be considered “informal” supports while that from professionals is generally paid help, although family members may receive some payment under the LAH and OAW waivers. Those who reported some help were also asked about their satisfaction with that help. Tables 13 and 14 show selected aggregated results on questions of help and satisfaction by the primary grouping categories for this study (Table 13) and by counts of ADLs (Table 14).

Among 786 respondents who reported recent help in the community, 90.6 percent received help from family and/or friends and 48.2 percent received help from professional aides (see Table 13). These respondents reported an average of 23 hours of help from family and friends in a typical day. A slightly higher percentage of those not designated NHLOC reported having help from family and friends than those with an NHLOC. Those who were 65 to 84 years of age in the “Other” category also tended to report higher average hours of support from family and friends. One possible, perhaps obvious, explanation for the patterns in these results is that those who do not now receive Medicaid LTC services have more informal community supports that offset the need for Medicaid services. It is important to note that there were several categories of potential support, particularly for family and friends, each of which could account for hours of help. Thus, total hours of support could be more than 23 in many instances. Moreover, support in this case may be more broadly understood to be generally available rather than on-going direct care. Examining these types of results in more detail may help establish better estimates of the extent to which CCOs under CommunityChoice can/should/will be expected to provide differing levels of coordination of support services, regardless of how those services are provided.

Almost a quarter of respondents who reported currently getting help (197 of 786) also reported that they did not need help for any of the six listed ADLs. Interestingly, nearly 27 percent of those reporting no specific ADL need also reported having paid help—for an average of almost 16 hours a day. In absolute number terms, this result seems to be consistent with the earlier result that slightly more than 18 percent of those who had a known NHLOC reported no specific ADL need (see Table 7). As noted earlier, this suggests that there are important aspects of functional support need that are not picked up in the standard list of ADLs, which may include clinical supports as well as help with chores and cooking and more incidental aspects of independent living. These results also raise important tangential questions about the relationship between functional status as reflected in ADLs and how NHLOC is now determined in Maryland. In any event, results from this survey suggest that informal supports now play a substantial role in the lives of Medicaid recipients and that professional supports play a significant role both for those who currently receive that care through the Medicaid program and those who do not.



In general, satisfaction with care from professionals was high (more than 85 percent) and noticeably higher than satisfaction for care from family and friends. Satisfaction with care from family and friends was lowest among those under 50 years of age; however, there were more missing data among this group, indicating hesitancy or unwillingness to comment about help from this source.

Tables 15 and 16 show results on a limited number of measures of access to care. A high percentage of the respondent population has a regular doctor (96.4 percent) and has had recent clinical care (87.4 percent). More than 25 percent of respondents use special transportation to get to the doctor's office. Respondents were also asked about the level of crime they perceive locally. Roughly 12 percent reported crime as a big problem in their neighborhoods. Crime was a bigger problem for respondents under age 65 (18.6 percent) and those with no NHLOC. Table 15 reflects results for the total population, as well as by age categories and NHLOC status, but also a mutually exclusive categorization of living arrangements. Interestingly, crime was reported as more of a problem for those who lived alone (14.4 percent) or with family members only (11.4 percent) than for those who live with others who are not family. Lower results on attitude toward crime among those who live with "Others" may reflect group settings that are not picked up in survey questions, as noted in the discussion regarding Table 11 above.

Table 17 includes selected measures from the SF-12 Health Status survey embedded in the larger survey questionnaire. Slightly more than 65 percent of respondents reported that their health was fair or poor. This is noticeably higher than the 49 percent reported by Komisar, Feder, and Kasper (2005), which was limited to those who were at least 65 years of age. However, in the earlier study, respondents were asked to characterize their health as compared to others of the same age, whereas age is not mentioned in the comparable question for this survey.

Some results across sub-groupings of individuals are curious, although this may be the results of small numbers in many cases. Two of 38 recipients (5.3 percent) ages 21 to 49 with an NHLOC reported excellent health. Just more than 6 percent (4 of 64 recipients) who reported needing help for all six ADLs reported excellent or very good health. Other results may reflect the level of help some recipients do (or do not) receive. For example, higher percentages of those designated as "Other" among those under 65 reported fair or poor health as opposed to those with an NHLOC. By definition, this group is designated as disabled under Medicare yet they report poorer general health overall than comparable recipients who are receiving some level of Medicaid support services (that is, those designated NHLOC).

SF-12 composite scores on physical and mental health are shown in the rightmost columns of Table 17. Unadjusted national estimates for those measures are 50.12 and 50.04, respectively. Results on those measures for this study can be expected to be much lower than that average because the survey population is older and generally more disabled than the national population as a whole. The physical composite score (PCS) for the survey respondent sample as a whole was 34.72, with a low of 27.39 (6 ADLs) and a high of 36.79 (0 ADLs) across the groupings included in Table 17. These scores are consistently lower than the 25<sup>th</sup> percentile score reported for the nation as a whole, although they are closer on average to the 25<sup>th</sup> percentile of the



national values for those 65 to 74 years of age (35.83). The mental health composite score was 46.41, overall, which was generally higher than the PCS across respondents and slightly higher than the 25<sup>th</sup> percentile (45.13) reported for the nation as a whole.

Generally, more detailed measures of access and health status will be drawn from Medicaid and, if available, Medicare data sources in subsequent analyses.



Table 13: Source of Help and Satisfaction Among Respondents (Measures by Age Cat. & NHLOC)

	Reported Help	Has Help from Family & Friends				Professional/Paid Help				
		Help from Family & Friends	Avg. Hrs in a Day from Fam/Friends	Satisfied with Help	Not Satisfied with Help	Help from Professional	Avg. Hrs in a Day from Professional	Satisfied with Help	Not Satisfied with Help	
1	Total	786	90.6%	23.0	72.2%	5.9%	48.2%	12.6	92.9%	5.3%
<i>Age Category</i>										
2	21-64	287	88.5%	19.9	57.5%	4.3%	41.1%	15.6	91.5%	5.9%
3	65 and Over	499	91.8%	24.8	80.3%	6.8%	52.3%	11.2	93.5%	5.0%
<i>NHLOC Status</i>										
4	NHLOC	320	84.7%	23.5	68.3%	6.3%	84.7%	12.6	95.2%	4.1%
5	Other	466	94.6%	22.7	74.6%	5.7%	23.2%	12.5	87.0%	8.3%
<i>AgeCat. &amp; NHLOC Status</i>										
<i>21-49</i>										
6	NHLOC	34	82.4%	20.8	25.0%	0.0%	88.2%	13.5	90.0%	10.0%
7	Other	104	93.3%	18.0	57.7%	5.2%	26.0%	23.4	85.2%	11.1%
<i>50-64</i>										
8	NHLOC	56	75.0%	22.6	52.4%	7.1%	83.9%	15.8	97.9%	2.1%
9	Other	93	93.5%	20.3	70.1%	3.4%	15.1%	3.9	85.7%	0.0%
<i>65-74</i>										
10	NHLOC	39	76.9%	20.9	83.3%	10.0%	84.6%	10.9	97.0%	3.0%
11	Other	78	96.2%	25.1	85.3%	6.7%	23.1%	15.4	88.9%	5.6%
<i>75-84</i>										
12	NHLOC	75	85.3%	22.0	71.9%	9.4%	77.3%	6.3	94.8%	5.2%
13	Other	94	94.7%	27.9	77.5%	10.1%	25.5%	10.0	79.2%	16.7%
<i>=&gt; 85</i>										
14	NHLOC	116	92.2%	26.2	79.4%	4.7%	88.8%	15.0	95.1%	2.9%
15	Other	97	95.9%	23.0	84.9%	3.2%	25.8%	5.9	96.0%	4.0%

Table 14: Source of Help and Satisfaction Among Respondents (Percent by Number of ADLs)

ADL Count	Reported Help	Has Help from Family & Friends			Professional/Paid Help					
		Help from Family & Friends	Avg. Hrs in a Day from Fam/Friends	Satisfied with Help	Not Satisfied with Help	Help from Professional	Avg. Hrs in a Day from Professional	Satisfied with Help	Not Satisfied with Help	
1	0	91.4%	21.7	73.9%	2.8%	26.9%	15.8	90.6%	1.9%	
2	1	93.3%	22.5	73.2%	4.6%	35.1%	12.7	93.2%	4.1%	
3	2	86.8%	18.3	70.7%	7.1%	53.5%	10.0	96.7%	3.3%	
4	3	86.7%	29.9	72.3%	6.2%	68.0%	12.1	88.2%	11.8%	
5	4	92.4%	28.1	73.8%	11.5%	68.2%	9.8	100.0%	0.0%	
6	5	95.5%	21.9	69.8%	7.9%	71.2%	14.8	91.5%	6.4%	
7	6	83.3%	25.5	66.0%	10.0%	81.7%	13.1	89.8%	10.2%	
<i>ADL Count &amp; Age Category</i>										
<i>0 ADLs</i>										
8	Ages 21-64	86.7%	18.0	58.3%	4.2%	28.9%	20.6	87.5%	4.2%	
9	65 and Over	94.7%	24.2	84.3%	1.9%	25.4%	11.9	93.1%	0.0%	
<i>1 ADL</i>										
10	Ages 21-64	92.2%	19.4	60.6%	2.8%	28.6%	15.3	95.5%	0.0%	
11	65 and Over	93.9%	24.4	80.5%	5.7%	38.9%	11.6	92.2%	5.9%	
<i>2 ADLs</i>										
12	Ages 21-64	87.5%	15.5	57.1%	2.9%	40.0%	7.3	100.0%	0.0%	
13	65 and Over	86.5%	19.8	78.1%	9.4%	60.8%	10.9	95.6%	4.4%	
<i>3 ADLs</i>										
14	Ages 21-64	84.0%	19.6	71.4%	4.8%	60.0%	12.1	80.0%	20.0%	
15	65 and Over	88.0%	34.8	72.7%	6.8%	72.0%	12.1	91.7%	8.3%	
<i>4 ADLs</i>										
16	Ages 21-64	95.5%	26.1	61.9%	9.5%	54.5%	12.8	100.0%	0.0%	
17	65 and Over	90.9%	29.1	80.0%	12.5%	75.0%	8.7	100.0%	0.0%	
<i>5 ADLs</i>										
18	Ages 21-64	100.0%	27.7	50.0%	0.0%	61.1%	26.3	100.0%	0.0%	
19	65 and Over	93.8%	19.6	77.8%	11.1%	75.0%	11.3	88.9%	8.3%	
<i>6 ADLs</i>										
20	Ages 21-64	72.7%	23.5	25.0%	12.5%	81.8%	14.7	83.3%	16.7%	
21	65 and Over	89.5%	26.4	85.3%	8.8%	81.6%	12.2	93.5%	6.5%	

Table 14: Source of Help and Satisfaction Among Respondents (Percent by Number of ADLs) (Cont.)

ADL_Count	Reported Help	Has Help from Family & Friends				Professional/Paid Help				
		Help from Family & Friends	Avg. Hrs in a Day from Fam/Friends	Satisfied with Help	Not Satisfied with Help	Help from Professional	Avg. Hrs in a Day from Professional	Satisfied with Help	Not Satisfied with Help	
<i>ADL Count &amp; NHLOC Status</i>										
<i>0 ADLs</i>										
22	NHLOC	29	72.4%	17.9	52.4%	0.0%	69.0%	14.3	100.0%	0.0%
23	Other	168	94.6%	22.2	76.7%	3.1%	19.6%	16.8	84.8%	3.0%
<i>1 ADL</i>										
24	NHLOC	60	83.3%	26.5	64.0%	6.0%	83.3%	14.8	96.0%	2.0%
25	Other	148	97.3%	21.2	76.4%	4.2%	15.5%	8.1	87.0%	8.7%
<i>2 ADLs</i>										
26	NHLOC	54	81.5%	14.6	65.9%	6.8%	85.2%	10.8	100.0%	0.0%
27	Other	60	91.7%	21.2	74.5%	7.3%	25.0%	7.2	86.7%	13.3%
<i>3 ADLs</i>										
28	NHLOC	41	82.9%	24.2	70.6%	5.9%	90.2%	10.0	89.2%	10.8%
29	Other	34	91.2%	36.0	74.2%	6.5%	41.2%	17.8	85.7%	14.3%
<i>4 ADLs</i>										
30	NHLOC	41	90.2%	28.1	81.1%	8.1%	87.8%	8.3	100.0%	0.0%
31	Other	25	96.0%	28.0	62.5%	16.7%	36.0%	15.9	100.0%	0.0%
<i>5 ADLs</i>										
32	NHLOC	47	95.7%	23.1	75.6%	4.4%	85.1%	16.5	92.5%	5.0%
33	Other	19	94.7%	18.8	55.6%	16.7%	36.8%	4.9	85.7%	14.3%
<i>6 ADLs</i>										
34	NHLOC	48	83.3%	28.0	62.5%	10.0%	87.5%	13.5	90.5%	9.5%
35	Other	12	83.3%	15.4	80.0%	10.0%	58.3%	10.9	85.7%	14.3%

Table 15: Selected Measures of Access Among Respondents (Percent by Age Cat., NHLOC, Living Arrangement)

	Persons	Has Regular Doctor	Recently Seen Regular Doctor	Uses Special Transport.	Is Accompanied to Doctor	Wait List for Group Setting	Wait List for Support Services	Crime is a Big Problem
1	Total	96.4%	87.4%	25.5%	59.7%	4.2%	2.2%	12.1%
<i>Age Category</i>								
2	21-64	95.7%	87.1%	28.4%	49.9%	5.7%	1.9%	18.6%
3	65 and Over	96.8%	87.6%	23.5%	66.5%	3.1%	2.5%	7.6%
<i>NHLOC Status</i>								
4	NHLOC	97.1%	89.0%	38.2%	81.2%	3.9%	5.5%	7.6%
5	Other	96.2%	87.0%	22.6%	54.9%	4.2%	1.5%	13.2%
<i>Living Arrangements</i>								
6	Alone or Unknown*	96.3%	87.5%	30.0%	46.0%	4.1%	2.2%	14.4%
7	w/Other Non-Family	97.2%	91.5%	25.5%	59.4%	10.4%	1.9%	4.7%
8	w/Family	96.3%	86.7%	22.3%	69.1%	3.6%	2.3%	11.4%
9	w/Family & Other	97.9%	93.6%	21.3%	80.9%	4.3%	2.1%	6.4%

\* This may include some individuals in Assisted Living or other group arrangements who consider themselves living alone.

Table 16: Selected Measures of Access Among Respondents (Percent by Number of ADLs)

ADL Count	Persons	Has Regular Doctor	Recently Seen Regular Doctor	Uses Special Transport.	Is Accompanied to Doctor	Wait List for Group Setting	Wait List for Support Services	Crime is a Big Problem	
1	1,423	96.3%	87.2%	21.8%	49.5%	4.2%	1.3%	12.8%	
2	226	96.9%	88.5%	28.8%	75.2%	5.3%	2.2%	11.1%	
3	124	96.8%	91.1%	31.5%	83.9%	4.0%	5.6%	11.3%	
4	81	96.3%	82.7%	28.4%	85.2%	7.4%	6.2%	17.3%	
5	75	97.3%	86.7%	45.3%	90.7%	2.7%	2.7%	8.0%	
6	69	97.1%	88.4%	39.1%	89.9%	1.4%	5.8%	8.7%	
7	64	92.2%	85.9%	42.2%	84.4%	0.0%	7.8%	4.7%	
<i>ADL Count &amp; Age Category</i>									
<i>0 ADLs</i>									
8	621	95.3%	86.8%	23.3%	41.4%	5.6%	1.1%	18.4%	
9	802	97.1%	87.5%	20.6%	55.9%	3.1%	1.4%	8.5%	
<i>1 ADL</i>									
10	84	98.8%	91.7%	32.1%	61.9%	7.1%	0.0%	20.2%	
11	142	95.8%	86.6%	26.8%	83.1%	4.2%	3.5%	5.6%	
<i>2 ADLs</i>									
12	45	95.6%	86.7%	31.1%	75.6%	4.4%	6.7%	22.2%	
13	79	97.5%	93.7%	31.6%	88.6%	3.8%	5.1%	5.1%	
<i>3 ADLs</i>									
14	27	96.3%	81.5%	51.9%	77.8%	7.4%	7.4%	29.6%	
15	54	96.3%	83.3%	16.7%	88.9%	7.4%	5.6%	11.1%	
<i>4 ADLs</i>									
16	25	96.0%	84.0%	60.0%	88.0%	8.0%	4.0%	20.0%	
17	50	98.0%	88.0%	38.0%	92.0%	0.0%	2.0%	2.0%	
<i>5 ADLs</i>									
18	19	94.7%	84.2%	47.4%	84.2%	5.3%	5.3%	10.5%	
19	50	98.0%	90.0%	36.0%	92.0%	0.0%	6.0%	8.0%	
<i>6 ADLs</i>									
20	22	95.5%	90.9%	68.2%	86.4%	0.0%	9.1%	4.5%	
21	42	90.5%	83.3%	28.6%	83.3%	0.0%	7.1%	4.8%	

Table 16: Selected Measures of Access Among Respondents (Percent by Number of ADLs) (Cont.)

ADL Count	Persons	Has Regular Doctor	Recently Seen Regular Doctor	Uses Special Transport.	Is Accompanied to Doctor	Wait List for Group Setting	Wait List for Support Services	Crime is a Big Problem
<i>ADL Count &amp; NHLOC Status</i>								
<i>0 ADLs</i>								
22	NHLOC	97.1%	94.3%	34.3%	64.3%	2.9%	8.6%	10.0%
23	Other	96.3%	86.8%	21.1%	48.8%	4.3%	0.9%	12.9%
<i>1 ADL</i>								
24	NHLOC	96.8%	92.1%	38.1%	77.8%	9.5%	3.2%	4.8%
25	Other	96.9%	87.1%	25.2%	74.2%	3.7%	1.8%	13.5%
<i>2 ADLs</i>								
26	NHLOC	96.6%	91.5%	39.0%	89.8%	6.8%	8.5%	5.1%
27	Other	96.9%	90.8%	24.6%	78.5%	1.5%	3.1%	16.9%
<i>3 ADLs</i>								
28	NHLOC	100.0%	84.4%	28.9%	82.2%	6.7%	4.4%	15.6%
29	Other	91.7%	80.6%	27.8%	88.9%	8.3%	8.3%	19.4%
<i>4 ADLs</i>								
30	NHLOC	97.8%	82.6%	43.5%	89.1%	0.0%	0.0%	6.5%
31	Other	96.6%	93.1%	48.3%	93.1%	6.9%	6.9%	10.3%
<i>5 ADLs</i>								
32	NHLOC	100.0%	87.8%	40.8%	89.8%	0.0%	4.1%	10.2%
33	Other	90.0%	90.0%	35.0%	90.0%	5.0%	10.0%	5.0%
<i>6 ADLs</i>								
34	NHLOC	92.0%	86.0%	44.0%	82.0%	0.0%	8.0%	2.0%
35	Other	92.9%	85.7%	35.7%	92.9%	0.0%	7.1%	14.3%

Table 17: Selected SF-12 Results: General Health & Composite Scores for Physical and Mental Health

	Persons	Report General Health As...*					Composite Score**	
		Excellent	Very Good	Good	Fair	Poor	Physical Health	Mental Health
1	Total Reporting 2,057	2.9%	8.8%	22.3%	40.2%	25.9%	34.72	46.41
<i>Age Category</i>								
2	21-64 842	3.1%	7.5%	20.0%	42.9%	26.6%	34.22	42.73
3	65 and Over 1,215	2.7%	9.7%	23.9%	38.3%	25.4%	35.08	48.99
<i>NHLOC Status</i>								
4	NHLOC 380	1.1%	6.8%	21.6%	36.8%	33.7%	30.92	45.89
5	Other 1,677	3.3%	9.2%	22.4%	40.9%	24.2%	35.53	46.52
<i>AgeCat. &amp; NHLOC Status</i>								
<i>21-49</i>								
6	NHLOC 38	5.3%	13.2%	39.5%	26.3%	15.8%	35.59	47.54
7	Other 389	5.1%	10.8%	23.9%	40.9%	19.3%	37.59	42.32
<i>50-64</i>								
8	NHLOC 67	1.5%	6.0%	23.9%	40.3%	28.4%	32.18	43.49
9	Other 348	0.9%	3.4%	12.6%	47.4%	35.6%	30.76	42.59
<i>65-74</i>								
10	NHLOC 56	0.0%	8.9%	16.1%	39.3%	35.7%	31.43	46.95
11	Other 380	2.9%	9.2%	27.4%	38.9%	21.6%	36.52	49.33
<i>75-84</i>								
12	NHLOC 91	0.0%	6.6%	16.5%	41.8%	35.2%	30.14	47.36
13	Other 348	2.9%	12.1%	24.7%	37.6%	22.7%	36.98	50.23
<i>=&gt; 85</i>								
14	NHLOC 128	0.8%	4.7%	21.1%	33.6%	39.8%	29.17	45.18
15	Other 212	5.2%	11.3%	23.1%	39.2%	21.2%	35.51	49.60

Table 17: Selected SF-12 Results: General Health & Composite Scores for Physical and Mental Health (Cont.)

	Persons	Report General Health As...					Composite Score	
		Excellent	Very Good	Good	Fair	Poor	Physical Health	Mental Health
	<i>ADL Count</i>							
16	0	3.5%	10.4%	23.7%	41.2%	21.1%	36.79	47.43
17	1	0.4%	7.1%	17.7%	44.7%	30.1%	32.10	43.95
18	2	2.4%	4.9%	21.1%	31.7%	39.8%	29.79	44.18
19	3	3.7%	3.7%	13.6%	43.2%	35.8%	29.27	42.66
20	4	0.0%	4.0%	24.0%	30.7%	41.3%	28.03	44.66
21	5	0.0%	4.3%	23.2%	33.3%	39.1%	28.11	45.02
22	6	3.1%	3.1%	17.2%	31.3%	45.3%	27.39	43.93
	<i>Living Arrangements</i>							
23	Alone or Unknown***	2.1%	9.8%	21.4%	40.9%	25.9%	34.89	46.97
24	w/Other Non-Family	4.8%	9.5%	22.9%	40.0%	22.9%	36.50	44.08
25	w/Family	3.4%	8.1%	23.1%	39.2%	26.2%	34.44	46.45
26	w/Family & Other	0.0%	6.4%	17.0%	51.1%	25.5%	34.62	41.23

\* Includes those who responded to the question.

\*\* Scores reflect 1,868 respondents with no report of missing values in any SF12 question.

\*\*\* This may include some individuals in Assisted Living or other group arrangements who consider themselves living alone.

## Summary

The primary purpose of this report is to describe the final refinement and conduct of an initial survey to examine the distribution of need for support for certain activities of daily living among a CommunityChoice-eligible population in Maryland. Secondly, this report aims to provide a preliminary look at the results. The longer-range objective underlying this study is to provide a baseline context within which to examine the relationships between ADLs, formal and informal community supports, and Medicaid resource use. The Center's intention is to collect and examine data on resource use both prior and subsequent to a set point in time relative to the survey results, tentatively set for June 1, 2006 (as of this writing), to inform the development of potential methods to use information on recipients' functional status in rate setting as well as performance assessment under CommunityChoice. More broadly, results from this survey and subsequent analyses are expected to help inform ongoing considerations of other potential programs and/or refinements of existing programs that provide LTC services to eligible Medicaid recipients whether or not CommunityChoice is eventually implemented in its currently proposed form.

While preliminary results from this survey provide important information about the distribution of ADL support need and the level and types of support now utilized to address that need, more considered work is needed to explore these results further, even aside from the integration of other data sources. It is also important to note that, because of the lag involved in reporting claims, it will take four to six months to accrue sufficiently comprehensive data on Medicaid resource use to dependably establish appropriate measures of prior service use and costs. In the meantime, Center staff will be looking for ways both to refine the preliminary results reported here and to include additional measures of prior service use to articulate the distribution of the survey results more effectively. The remainder of this section briefly addresses a few key highlights regarding issues raised so far. Although some general next steps are also outlined below, the Center will be working with representatives at DHMH during the coming months to set both short- and long-term priorities for subsequent analyses.

*Issues with the Administration of the Survey.* The conduct of the survey itself raised a number of issues involved in collecting data on functional status in particular, but also initial patient assessment data more generally—at least in the context of CommunityChoice. One overarching issue that DHMH has already recognized is that the contact information available to the Center and, by extension, to other representatives of DHMH, is relatively poor. Discussions within DHMH as well as within advisory committees to support the program have explored alternatives to establish an initial assessment of enrollees under CommunityChoice. Final details regarding what that initial assessment protocol will include and how it will be administered are still unknown. Nevertheless, from a practical standpoint it will be important for DHMH to include plans to improve the contact information it maintains on Medicaid recipients as part of its broader planning for an initial enrollment and preliminary assessment of recipients under CommunityChoice.



Although this may be explored in more detail in subsequent analysis, a cursory examination of the data presented above suggests that the weakness evident in the contact information available for this study has not necessarily markedly skewed the survey results. For example, the distribution of recipients in the sampling frame who could not be reached because of problems with their telephone numbers and the distribution of their associated CY 2005 PMPM costs were reasonably comparable to the eligible population as a whole. Excluding some individuals where a given telephone number was associated with multiple recipients may have skewed the survey results slightly in the direction of under-representing the extent of ADL support need in the community. This issue does tangentially indicate that it would be beneficial, in the future, to include an explicit question regarding the current living circumstances of recipients, such as a permanent or temporary home, apartment, assisted living, or shelter. On the whole, however, the sampling scheme across age categories and NHLOC status seems to have otherwise helped to ensure a representative final sample of respondents.

Potential respondents were excluded if they were receiving institutional care at the time of the survey. This may help explain the relatively low CY 2005 PMPM costs for survey respondents with no NHLOC (\$219, see Table 5) to the extent that individuals, such as those in the “duplicate telephone number” group, were receiving institutional care (but not otherwise flagged as such because of available claims data). At the same time, some of these individuals should have been excluded from the community-dwelling population in the first place. When more recent data become available, more analysis is needed to refine the basic categorization of recipients used in this report, which may include re-assessing who is defined as institutionalized versus community-dwelling. There may also be ways to categorize survey respondents (in the community) that more appropriately reflect prior resources use experience than the primary split between NHLOC and no NHLOC reflected in this report. A more extended time period within which to identify prior institutional care may help clarify patterns of prior and, presumably, subsequent resources use related to functional status. Other markers, such as prior inpatient hospital stays or the presence of certain chronic conditions, may also be useful to explore. However, some of these indicators may be more appropriate in performance assessment than as criteria for rate setting.

Those who either refused to participate, could not be reached for a callback, or fell into a catchall group of other dispositions were distributed much like the population as a whole except for a high percentage of those who were 85 years of age and older. In general, that older group of recipients proved to be difficult to reach and include in the survey. This is not particularly surprising, but it does serve as a reminder that special attention may be needed to assess and accommodate this notably high resource and otherwise NHLOC-dependent group under CommunityChoice. Those excluded because of language were somewhat older and were more likely to be NHLOC recipients. However, except for a few isolated high cost cases, they tended to exhibit patterns of prior costs that were much like the population as a whole.

*Preliminary Implications of Survey Results.* The kind of ongoing efforts just described to refine how the survey population is categorized relative to an appropriate point in time are likely to moderate specific preliminary survey results as well, although those changes are likely to be



modest. The preliminary results outlined above do provide a few broad indicators that are not likely to change significantly but that have important implications for CommunityChoice. Perhaps the most important of those involves the dual result of the extent to which those who do not have an NHLOC reported needing support and the extent to which those who do have an NHLOC reported no specific ADL support need. More than 5 percent of community-dwelling recipients who do not have an NHLOC as defined for this study reported needing support for three or more ADLs. More than 18 percent of respondents who were known to have an NHLOC did not report that they needed support for any specific ADL.

Further refinement of how NHLOC status is defined may potentially reduce the number of high ADL need cases among those defined as not NHLOC to the extent that such recipients otherwise indicate an NHLOC. In other words, some of that result may be explained away by better categorization based on additional measures of prior service use. It is also the case that recipients must seek NHLOC status. Thus, that result may also provide some insight into the extent to which CCOs may “find” need among enrollees, whether or not those recipients initially seek an NHLOC designation.

Those who have an NHLOC (i.e., because they receive waiver services or medical day care that require some level of certification already) and do not report the need for help for any specific ADL are potentially more troubling, at least with respect to estimating what the service needs may be under CommunityChoice. As noted previously, this last result may be due in part to something in the wording of the survey questionnaire that failed to identify what kind of support is actually needed by some respondents. However, this result may also be related to the current procedure to get an NHLOC. For example, the Maryland form (3871b) that is used to determine an NHLOC for LTC support services is designed so that individuals who receive a specific threshold score are eligible for such services. Many individuals who do not meet that initial threshold score are subsequently approved for an NHLOC based on other criteria. It is beyond the scope of this report to establish a link between those with an NHLOC who report no ADL need in this survey and those who receive a low score on the 3871b. However, it does raise the broader concern that whatever tool is used to establish the equivalent of an NHLOC under CommunityChoice needs to be sufficiently comprehensive, valid, and reliable to appropriately reflect the “true” spectrum of need that CCOs are expected to manage.

Preliminary results from this survey also show that those who report the need for support for specific ADLs, as well as those who otherwise report that they receive help, currently receive a significant amount of that help from family and friends. An appreciable percentage of recipients with no formal NHLOC receive professional support services, presumably not covered by Medicaid. It will be critically important for the financial viability of CommunityChoice that DHMH establish clear parameters to identify the level of support that each recipient should expect to receive and fair expectations for what is required of CCOs under the program. Some of that may be tangentially addressed in whatever final instrument is used to assess recipients upon entry to the program as well as how that information is tied to the rate setting system. If that assessment instrument is not applied universally to the CommunityChoice population, DHMH may need to establish some other means to determine recipient and CCO provider expectations



under the program. Most of this may need to be addressed through the expectations that DHMH establishes with CCOs. In any case, those expectations may be influenced by the results of this study as well as influence how this study's results are interpreted.

For example, under CommunityChoice, CCOs will be required to assign a care coordinator to recipients who receive personal care services and a comprehensive support team if they are otherwise eligible for an NHLOC. The underlying premise of the program is that a broader distribution of support services in the community will moderate the extent to which providers and recipients will rely on more expensive institutional care and improve recipients' quality of life. Preliminary results from this survey suggest that there is significant need for support from informal and professional sources that is currently unrecognized, at least in financial terms, under existing programs. What formal parameters can realistically be put in place to fairly limit services provided by CCOs to those that are necessary and appropriate while accomplishing both that broader distribution of services and the financial viability of the program?

*Next Steps.* While a host of issues suggested by these preliminary results merit more detailed analysis, the focus and order of subsequent analysis will be largely determined through consultation with DHMH and shaped by available resources. As noted above, the Center will be working with DHMH during the coming months to set both short- and long-term priorities for subsequent analyses.

In the meantime, the most immediate concern for the Center will be to focus most directly on further work to refine how the CommunityChoice population should be categorized for subsequent analyses. Potential refinements are likely to include how current and prior Medicaid program service use is reflected in rules to identify NHLOC status, as well as additional demographics such as sex. Given those refinements, the Center will begin to explore alternative ways to use the survey results to estimate what might otherwise be referred to as unmet need. This may then be used to estimate, for example, the level of care coordination and comprehensive support team efforts that might be required under CommunityChoice.

Center staff would also like to further explore the relationship between both formal and informal community LTC supports and the use of other public program resources, including Medicaid institutional care and acute care resource use. The Center will also be exploring ways to acquire more recent comprehensive Medicare claims data that can be integrated with existing Medicaid and Medicare data files, as well as other sources of funding to support such analysis to the extent that it goes beyond the immediate priorities set by DHMH.

