

**INTERVIEWING POPULATIONS WITH DISABILITIES BY TELEPHONE:
SURVEY DESIGN AND OPERATIONS**

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States are modifying their Medicaid programs to offer services through managed care rather than under traditional fee-for-service arrangements. As part of this transition, more and more low-income Supplemental Security Income (SSI) recipients are being enrolled in Medicaid managed care plans. The diverse and complex needs of SSI enrollees are a challenge for managed care. SSI enrollees' disabilities encompass physical or sensory disabilities (including blindness and deafness), mental illness, and mental retardation. Managed care plans have less experience serving people with disabilities than they do in serving people without disabilities; thus, they may lack expertise arranging for their complex care needs. Moreover, the use of capitated payments in managed care systems produces an incentive to reduce service use.

As part of the Health Care Financing Administration's evaluations of Section 1115 Medicaid Reform Demonstrations, Mathematica Policy Research, Inc. (MPR) conducted computer-assisted telephone interview (CATI) surveys in order to assess how SSI recipients are faring in Medicaid managed care programs.¹ The surveys--conducted in Kentucky, New York, and Tennessee--addressed access to care, quality of care, and use of health services. MPR conducted more than 4,600 interviews. These were the first surveys of this type to be conducted solely by telephone for people with disabilities; therefore, we took care to accommodate their needs and to minimize proxy response. Our goals were: (1) give respondents with disabilities the opportunity to speak for themselves regarding issues that affect their health care, and (2) provide our clients with a cost-effective way to collect data from SSI recipients. Had these surveys been conducted face-to-face instead of

by telephone, they would have cost about four times as much--a cost that may well have been prohibitive.

Respondents appreciated the opportunity to participate in these surveys. Table 1 shows response

TABLE 1
RESPONSE RATES AND COOPERATION RATES,
BY STATE AND TYPE OF DISABILITY

| | Response Rate | Cooperation Rate | Self Response Rate |
|--------------------|---------------|------------------|--------------------|
| Tennessee | 67.3% | 96.5% | 87.0% |
| Physical | 70.2% | 95.3% | 93.4% |
| Mental illness | 67.5% | 96.2% | 90.4% |
| Mental Retardation | 62.0% | 97.8% | 81.4% |
| Unknown | 70.3% | 96.9% | 80.7% |
| Kentucky | 74.3% | 97.4% | 83.9% |
| Physical | 84.4% | 98.5% | 92.7% |
| Mental illness | 71.9% | 97.3% | 85.8% |
| Mental Retardation | 72.2% | 96.5% | 75.8% |
| Unknown | 71.5% | 97.5% | 74.6% |
| New York City | 57.5% | 92.8% | 78.8% |
| Physical | 60.9% | 91.8% | 86.9% |
| Mental illness | 53.3% | 87.4% | 85.1% |
| Mental Retardation | 55.9% | 97.3% | 69.0% |
| Unknown | 62.1% | 94.9% | 75.4% |
| Westchester County | 59.0% | 92.5% | 80.7% |
| Physical | 61.4% | 93.1% | 86.9% |
| Mental illness | 56.0% | 90.8% | 87.9% |
| Mental Retardation | 64.9% | 96.3% | 56.1% |
| Unknown | 56.4% | 91.5% | 76.7% |
| Total | 65.7% | 95.3% | 83.0% |
| Physical | 69.6% | 95.1% | 90.4% |
| Mental illness | 64.5% | 94.3% | 87.0% |
| Mental Retardation | 64.0% | 97.0% | 72.7% |
| Unknown | 65.3% | 95.4% | 77.1% |

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rates, cooperation rates, and self-response rates by state, as well as the type of disability, as defined in the SSI files. The cooperation rates were, on average, 95 percent, ranging from 94 percent for respondents with mental illness to 97 percent for respondents with mental retardation. The average self-response rate was 83 percent, but it varied considerably by type of disabling condition. Those with physical or sensory disabilities were the most likely to self-respond (90 percent); 87 percent of those with mental illness self-responded; and 73 percent of those with mental retardation answered for themselves. The only notable source of nonresponse was the inability to locate sample members by telephone. Sample frames were state Medicaid administrative records. Although the data quality varied from state to state, for the most part, these files either lacked addresses or telephone numbers, or they contained inaccurate contact information. Some files misreported current program eligibility. The poor quality of the data adversely affected survey response rates. For example, our response rates ranged from 58 percent in New York City to 74 percent in Kentucky.

This paper discusses the techniques used to design and conduct the surveys. To be successful, we had to overcome communication, stamina, and cognitive challenges. At the same time, it was critical that the questionnaire be as comparable as possible to the questionnaires of all types of Medicaid recipients conducted as part of larger evaluations of Medicaid managed care plans. To accomplish this, we (1) eliminated soft consonant sounds to overcome high-frequency hearing loss, (2) built in "breaks" for respondents, (3) incorporated neutral encouragement, (4) designed checks for unexpected responses, and (5) used structured probes for questions that might be difficult to understand. We selected experienced interviewers, but not necessarily those with special training in working with people with disabilities. We trained the interviewers on the challenges of interviewing people with disabilities by telephone and provided guidance for overcoming each challenge. We also provided sensitivity training regarding people with disabilities and modified usual interviewer performance measures, so interviewers would not be penalized for break-offs and long interviews. The sources of data for this discussion are (1) two pretests, conducted in April and June 1998; (2) data from the survey itself; and (3) debriefing sessions held with interviewers during and after the field period.

Challenges in Interviewing Disabled People by Telephone. As survey researchers, we collect data from persons with disabilities all the time. Usually, however, we are unaware that a particular respondent has a disabling condition--especially if the interview is being

conducted by telephone. The dilemma we faced in designing these surveys was that *every* sample member had a disability. Moreover, there was a wide range of disabilities, with varying degrees of severity; in addition, some sample members had multiple disabling conditions. Moreover, because the sample frame did not contain information about everyone's disabling condition, we could not design a survey that overcame all the possible challenges to every sample member. Instead, we attempted to address three broad categories of common challenges: (1) communications, (2) stamina, and (3) cognitive barriers. Communication challenges include both hearing and speech impairments. Stamina challenges include both physical and mental fatigue. Cognitive challenges include, but are not limited to, emotional disturbance, difficulty processing questions and responses, lack of complete or specific knowledge, and confusion about the purpose of the interview.

Design Techniques Used to Overcome These Challenges. The questionnaires featured four techniques designed to overcome these challenges. First, we reviewed the questionnaire administered to all types of Medicaid recipients to eliminate high frequency sounds (*s, z, t, f,* and *g*). High-frequency hearing loss is common. By replacing high frequencies with low frequencies, we could make the interview easier to hear. Following is an example of a question with numerous high-frequency sounds:

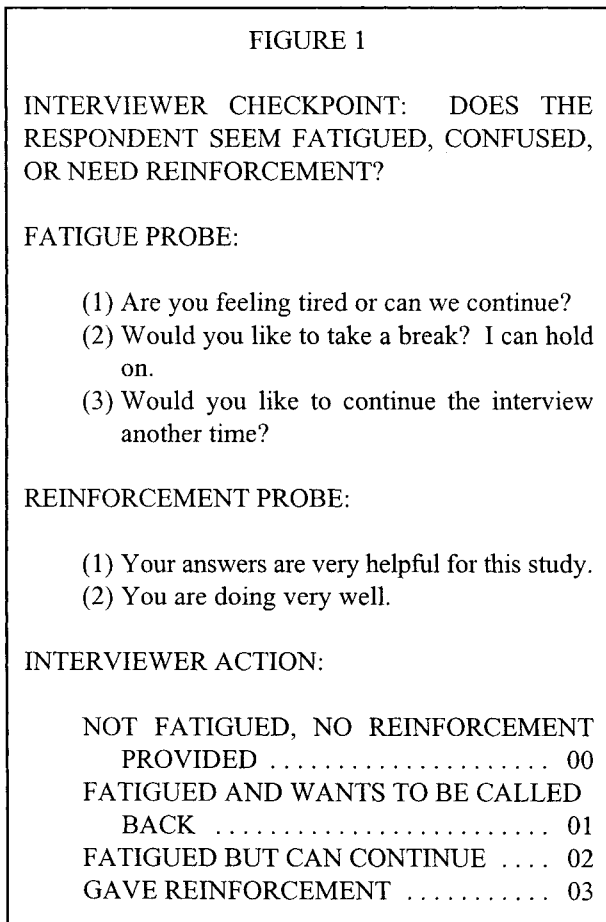
How satisfied are you with the overall quality of care you receive as a member of *NAME OF MANAGED CARE PLAN*? Are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?

Compare this with a version that uses low-frequency sounds:

How would you rate the overall quality of the medical care you get as a member of *NAME OF MANAGED CARE PLAN*? Is it excellent, very good, good, fair, or poor?

Second, we built in checkpoints for interviewers to assess if the respondent needed encouragement or was becoming too fatigued to continue the interview. The survey in Tennessee took, on average, 44 minutes to administer. The surveys in Kentucky and New York, took 22 minutes. Our pretest revealed that some respondents became fatigued, especially during the longer

interview. If the interviewer noticed that the respondent was fatigued, she asked the respondent if she wanted to continue or preferred to schedule another time to complete the survey. Every respondent in the pretest who preferred to be called back honored their commitment to continue. We also found, while pretesting, that it was useful to provide respondents with positive feedback about completing the survey task. Comments like, "Your answers are very helpful to this study" seemed to allay fears and put respondents at ease. Other reassuring comments that pretest interviewers used were, "there are no right or wrong answers to these questions" and "take your time." Based on these preliminary findings, we included three checkpoints in the interviews. The checkpoints ensured that interviewers stop and assess the respondent's ability to continue. They also provided prompts for interviewers to provide encouragement when necessary. Interviewers were required to record their actions at each checkpoint (see Figure 1).



Despite their disabling conditions, about three-quarters of the respondents were able to complete the 22-minute interview without special intervention from the

interviewer (Table 2). About half of the respondents completed the 44-minute interview without needing special intervention. These differences persisted across all disabling conditions.

TABLE 2
INTERVIEWER ACTIONS AT CHECKPOINTS

| | 22 Min | 44 Min |
|------------------------------------|--------|--------|
| Total Respondents (N =) | 2,852 | 916 |
| Percent Who Needed: | | |
| No Intervention | 73% | 51% |
| Some Intervention | 28% | 49% |
| Reinforcement only | 27% | 38% |
| Callbacks | 0% | 11% |
| No intervention but showed fatigue | 1% | 0% |

Not one respondent needed a break during the 22-minute interview. Eleven percent of the respondents needed a break during the longer interview. A second break was needed by more than half the respondents whose stamina or attention span was too low to complete the interview in one session (Table 3). Almost one-fourth of those who needed one break, however, were able to continue without further intervention. The others continued with interviewer encouragement alone. While the percentage who needed a break did not vary much by disabling condition, respondents with physical or sensory disabilities were most likely to need more than one break. These respondents tended to tire quickly or have difficulty using the phone for prolonged periods. Respondents with severe and persistent mental illness were most able to continue with no further intervention after a break.

Interviewers provided encouragement about one-third less often during the shorter interview than during the longer for those with physical or sensory disabilities or mental retardation. Respondents with mental illness needed almost as much encouragement during the shorter interview as during the longer one. This may be because the shorter interview focused on issues of mental and behavioral health. A subsample of respondents with schizophrenia needed almost no support or intervention during the 22-minute interview. We believe this group was getting enough behavioral health care--and

TABLE 3

OUTCOMES FOR SAMPLE MEMBERS WHO NEEDED CALLBACKS

| | Total | Physical | Mental Illness | Mental Retardation | Unknown |
|---|-------|----------|-------------------|-----------------------|---------|
| Respondents Who Needed Callbacks (N =) | 100 | 34 | 32 | 20 | 14 |
| Percent Who: | | | | | |
| Needed a second callback | 56% | 62% | 44% | 55% | 71% |
| Continued with no further intervention | 23% | 12% | 34% | 25% | 21% |
| Continued with only reinforcement | 21% | 26% | 22% | 20% | 7% |

medication--to manage their illness. Eighty-two percent reported taking a medication for a mental or emotional health problem. There was no 44-minute interview for this subgroup.

Generally, the interviewers perceived that respondents were happy to be interviewed and were reluctant to stop. Interviewers also reported that the checkpoints caused them to slow down the pace of the interview while also serving as a reminder that they were speaking with respondents who were likely to experience difficulties. Interviewers reported that the reinforcement was especially helpful for respondents who did not know the answer to a question or series of questions. For these respondents, interviewers discovered that the following sentence helped respondents relax and continue: "I know these questions are hard to answer and you are doing your best." The interviewers strongly recommended the use of encouragement in future surveys of populations with disabilities.

Third, we designed questions to "double check" unexpected responses. We expected people with disabilities and health insurance to have some doctor visits over the course of a year. Thus, for respondents who reported no medical visits in a year, we added a follow-up question, "Just to confirm, you have not gone to the doctor in the past year, is that correct?" Of the 198 adult respondents who initially reported no doctor visit in the previous year, 64 percent changed their answer after the confirmation question. Overall, there was no difference between proxy and self-responses. Sample members with mental illness were the least likely to change their response when presented with the confirmation question (55 percent), while sample members with mental retardation were the most likely to change their response (72 percent). This may be because they were in the group that had the most difficulty

understanding the original question or because they were most sensitive to providing socially desirable responses.

Fourth, we designed a series of structured probes to keep the interview for the respondents with disabilities as comparable as possible to the interview administered to all types of Medicaid recipients. The majority of questions worked well for most of the respondents with disabilities. Nevertheless, some respondents needed to have concepts defined. To the extent possible, we preserved the wording of the original question and supplemented it with standardized definitions and probes. To ensure that interviewers used them consistently, the probes appeared on the CATI screens in the order that we wanted interviewers to use them. If none of the probes helped the respondent, the interviewer was allowed to rephrase the question in a way she thought the respondent would understand. In the following examples, the new, structured probes appear in italics:

EXAMPLE 1:

For how many of the last twelve months, that is since MONTH AND YEAR 12 MONTHS AGO, have you been enrolled in NAME OF BEHAVIORAL HEALTH PLAN?

PROBE: For which months have you been enrolled?

PROBE: For how long have you been enrolled? Have you been enrolled in NAME OF BEHAVIORAL HEALTH PLAN all of that time?

EXAMPLE 2:

How long ago did you have your blood pressure taken by a doctor or other health professional?

PROBE: *When was the last time you had your blood pressure taken?*

PROBE: *The doctor or nurse puts a cuff around your arm, pumps it up, and listens with a stethoscope?*

Interviewers reported that they always read the main question first but often read the probe before waiting for the respondent to answer the main question. Interviewers reported that the structured probes were usually sufficient and that they rephrased questions most often for a subpopulation of Russian respondents in New York City and Westchester County.

Interviewer Selection, Training, and Supervision.

We staffed the surveys with experienced interviewers, but not with those who had special training in working with people with disabilities. The training program consisted of giving the usual background and purpose of the study, a question-by-question review of the instrument, contact protocols, refusal avoidance, and practice interviews. In addition, trainers addressed challenges the interviewers were likely to face. Training began with a sensitivity exercise designed to demonstrate that interviewers should be kind and have unconditional positive regard for respondents regardless of their limitations. Trainers stressed that the biggest barriers people with disabilities face and the hardest barriers to remove are other's negative attitudes and erroneous images of them. We discussed using positive rather than patronizing language and encouraged interviewers to place their focus on the individual first and the disability last. Trainers presented the three general challenges that persons with disabilities face completing telephone interviews and provided guidance for overcoming each one. Communication challenges were divided into hearing and speech impairments. To overcome hearing impairments, interviewers learned (1) to use a normal tone of voice and not restrict conversations to monosyllabic words, (2) to use controls on headsets to amplify outgoing sounds, and (3) to use a text telephone (TTY/TTD) relay operator if necessary. To overcome speech impairments, interviewers learned (1) to use controls on the headsets to amplify incoming sounds; (2) to not be afraid to ask the respondent to repeat what he or she said, (3) to be patient, because speech patterns become easier to discern after a

few minutes; (4) to repeat aloud what they did hear and understand if clarification is needed; and (5) to not pretend to understand something they did not. Instead, they were to go back and build from the point at which they did understand. We also explained that people with speech impairments may need extra time to organize their thoughts. Finally, we demonstrated that people with speech impairments may be unable to monitor their tone of voice. For example, a person with cerebral palsy may seem angry, when actually she or he is not, and people who slur words may seem drunk when they are not. We asked interviewers not to make assumptions about people based on their tone of voice. We reinforced this part of the training by having interviewers monitor an interview with a respondent with a severe speech impairment.

To overcome stamina challenges, we trained interviewers to be aware of behaviors that might suggest the respondent is too fatigued to continue. For instance, agitation and distraction can signal that the respondent is ready for a break. We encouraged interviewers to ask whether the respondent needed to schedule another time to continue, and to set appointments for times when the respondent is most alert.

To overcome cognitive challenges, we reviewed nonbiased, nondirective probing methods (silence, repeating the question, repeating the response categories, asking for more information, stressing generality, stressing subjectivity, and zeroing in). We showed interviewers (1) how to keep the respondent free of distractions, (2) instructed them to say the respondent's name often, and (3) suggested that they not exaggerate the inflection or tone of their voice (such as exaggerations call attention to themselves and can be distracting and confusing). We trained on active listening skills and patience. When the survey was over, interviewers reported that interviewing was not as difficult as the training suggested.

Finally, we recognized that conducting telephone interviews with people with disabilities would be challenging even for experienced, well-trained interviewers. Interviews take longer because questions need to be repeated and multiple sessions may be required. We made extra efforts to support the interviewers and reduce stress and burnout. We emphasized that our usual performance measures, such as hours per completed interview, are not as important as taking the time to be sure the respondent understands the question and is answering reliably. Supervisors reminded interviewers that break-offs are acceptable and desirable if respondents are fatigued. Supervisors and colleagues provided support during and after interviews and at regular debriefing sessions.

Conclusion. It is in our best interest as survey researchers to make surveys accessible to a broad spectrum of respondents at the lowest cost possible. Furthermore, it is our responsibility to collect the highest quality data possible. Most of the time, data of the highest quality can be collected directly from the people who are affected by the programs we study. We have demonstrated that, through careful instrument design and survey procedures, it is possible to conduct telephone interviews with persons with disabilities. Shorter interviews create less respondent burden and can be conducted with fewer break-offs and less need for encouragement from the interviewer than longer interviews. Ciemnecki et. al. (2000) report that even on longer interviews, the vast majority of respondents could answer for themselves, and that nearly all respondents could answer more than three-quarters of the questions in nearly all topic areas. Respondents were easily able to answer most questions about health functioning, demographics, access to care, satisfaction, and quality of care. When comparing patterns of answers across pairs of questions, they found consistency between reported factual measures of access to care and satisfaction with access to care.

In the end, the data proved to be sufficient for evaluating how disabled SSI enrollees fare in Medicaid managed care. In Tennessee, the data permitted an analysis of the diverse needs of disabled SSI beneficiaries, their participation in selecting their health plans and providers, and their access to care (Hill and Wooldridge 2000). The data also indicated that access to care and satisfaction levels differed among the beneficiaries in different managed care plans. Thus, the data collected through the telephone survey met the ultimate test in terms of providing useful information for assessing and planning managed care.

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