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# **Access to Care for Medicaid Beneficiaries with Disabilities in Rural Kentucky**

## **Revised Report**

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## **ACCESS TO CARE FOR MEDICAID BENEFICIARIES WITH DISABILITIES IN RURAL KENTUCKY**

About 8 million non-elderly adults and children receive Medicaid due to disability. The vast majority of these (about 78%) receive Supplemental Security Income (SSI) because of their disability and low-income (Crowley and Elias, 2003). These individuals suffer from a wide range of physical and mental impairments that are sufficiently serious to prevent them from working. There are two types of SSI beneficiaries on Medicaid: those who are dually eligible for Medicare and those who receive Medicaid alone. Dually eligible beneficiaries rely on Medicare as the primary payer for their health care, with Medicaid responsible for wrap-around coverage, i.e., cost-sharing amounts and non-Medicare-covered services like prescription drugs and long-term care. The remaining SSI beneficiaries rely wholly on Medicaid for their health care needs. Surprisingly little is known about these latter SSI beneficiaries, despite their high health care needs and potential vulnerability to access barriers.

Two recent studies have examined access to care and satisfaction for non-dually eligible adult SSI beneficiaries on Medicaid, one in New York City and Westchester County (Coughlin et al., 2002; Long et al., 2002), and the other in Memphis, Tennessee (Hill and Wooldridge, 2002 and 2003). These studies have found mixed results, with SSI beneficiaries reporting good access on some measures, and unmet needs on others. Almost all of the New York sample had made at least one outpatient visit in the past 12 months, for example, yet many still reported that they did not get all the care they needed. SSI beneficiaries are heterogeneous populations, with disabilities ranging from cerebral palsy to schizophrenia to multiple sclerosis. Only one of these studies examined differences in access by type of disability; Long et al. (2002) found that beneficiaries with serious mental illness were more likely to report unmet need for care. This New York City sample was relatively small, with only 236 respondents who were disabled by a serious mental illness.

The purpose of this study is to compare access to care by type of disability for a larger sample of adults who receive SSI and Medicaid because of their disability. It takes advantage of a survey originally intended to be the baseline for an evaluation of the impact of Medicaid managed care on persons with disability. Kentucky had implemented managed care in the state's two major cities (Lexington and Louisville) in 1997, and was planning to transition the remaining rural areas into the program several years later. Some policymakers were concerned about the potential impact of Medicaid managed care on access to care for persons with disabilities. A "pre managed care" survey was conducted of a random sample of SSI recipients with disabilities to obtain baseline information on access to both general medical and mental health care. When Kentucky later decided not to implement Medicaid managed care in its rural counties, the evaluation was cancelled. However, the baseline survey data provide detailed information on utilization of services by persons with disabilities.

This study seeks to build on the prior work in several ways. First, it is possible that respondents with disabilities, particularly mental disabilities, may not have accurately recalled their utilization. We used Medicaid claims to validate self-reports. Second, we examine not only utilization-based access measures, but also outcome measures, specifically hospital admissions for ambulatory-care sensitive conditions. Finally, these prior studies were based on urban SSI

populations that were largely black and Hispanic. This study focuses on a rural population that is predominantly white and non-Hispanic.

## **Data and Methods**

The study sample was drawn from state Medicaid eligibility files for SSI recipients aged 18 through 64. The Medicaid files had been merged with Social Security Administration records that contained information on the disability qualifying the individual for SSI. ICD-9 diagnosis codes were used to classify SSI recipients based on their type of disability: physical disability, mental illness, or mental retardation/developmental disability (MR/DD). The sample was limited to those persons residing in 39 rural counties in southern and eastern Kentucky (including Appalachia) where Medicaid managed care had not been implemented. SSI recipients who were also eligible for Medicare were excluded, as were nursing home residents. The sample was stratified by type of disability and region.

The survey was conducted using computer-assisted telephone interviewing techniques in 1999. A total of 1,329 persons completed the survey, including 476 persons with physical disability, 430 with mental illness, and 423 with MR/DD. The overall response rate was 75 percent, considerably higher than the 56-65 percent obtained in other surveys of SSI beneficiaries (Coughlin et al., 2002; Hill and Wooldridge, 2003).<sup>1</sup> Proxy respondents were used in 15 percent of cases when the person with disability was incapable of completing the telephone interview him or herself. This percent was comparable to those obtained in the other surveys. Proxies were used more often for persons with MR/DD than for those with other types of disabilities.

Inpatient and physician Medicaid claims were obtained for the twelve months preceding the interview. These claims were used to validate the self-reported information on medical care utilization. Hospital claims were also used to construct admission rates for ACS conditions. ACS conditions were defined, using ICD-9 diagnosis codes on hospital claims (UCSF, 1997).

Chi-squares and pairwise t-tests were used to test the statistical significance of differences between groups. All sample respondents were weighted to adjust for the probability of selection and for non-response. STATA software was used to adjust variances for the effects of unequal weights and unequal probabilities of selection.

## **Results**

### Descriptive Findings

Almost two-fifths of the study sample (39.3%) was eligible for SSI because of a physical disability. The remaining respondents were fairly evenly divided between mental illness (31.2%) and MR/DD (29.5%). Sociodemographic characteristics of the sample are shown in *Table 1*.

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<sup>1</sup> Coincidentally, the New York, Tennessee, and Kentucky surveys were all conducted by the same survey firm, Mathematica Policy Research. The higher response rate in Kentucky appears to be attributable to better address and telephone information obtained from state Medicaid files, possibly because these Medicaid beneficiaries were less transient than those in the two urban areas surveyed.

Respondents with MR/DD were significantly younger than other SSI beneficiaries; almost one-half (44.4%) were under 35 years of age, compared with only 22.7 percent of those with mental illness and 15.4 percent of those with physical disabilities. There are marked gender differences by type of disability as well. While MR/DD respondents were evenly divided between males and females, the majority of respondents in the other two groups were female. The vast majority of respondents were white, reflecting the racial/ethnic distribution of the state as a whole. (There are relatively few racial/ethnic minorities in Kentucky, and thus there were not large enough samples to show them individually.)

**Table 1**  
**Sociodemographic Characteristics by Type of Disability (percent distribution)**

	Physical Disability	Mental Illness	MR/DD
<b>Age (years):<sup>1</sup></b>		**a	**a, **b
18-34	15.4	22.8	44.2
35-44	17.8	27.5	24.1
45-54	28.9	30.5	18.4
55-64	37.9	19.2	13.3
<b>Female (%)</b>	60.9	72.0 **a	50.5 **a, **b
<b>White (%)</b>	94.7	94.8	93.2
<b>Education:<sup>1</sup></b>			**a, **b
<12 years high school	73.4	66.1	81.1
High school graduate	21.7	28.0	18.0
Some college	4.9	5.9	0.9

<sup>1</sup> Percentage distributions sum to 100 within category by column.

\*(\*\*) <sup>a</sup> Significantly different from respondents with physical disability at .05 (.01) level.

\*(\*\*) <sup>b</sup> Significantly different from respondents with mental illness at .05 (.01) level.

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999.

PROGRAMS: final 12b-c

There were significant differences by type of disability in educational attainment. Respondents with MR/DD were significantly less likely to have graduated from high school compared with either of the other two groups.

Not surprisingly, the vast majority of SSI beneficiaries reported themselves to be in fair or poor health (see *Table 2*), and many reported limitations with performing both activities of daily living (ADL) and instrumental activities of daily living (IADL). Nevertheless, there were pronounced differences by type of disability. Respondents with physical or mental disabilities were significantly more likely to report that their current health status was poor compared with those with MR/DD. (The excellent and very good categories were combined due to the very small number of responses in these two categories.) When asked to compare their health today to a year ago, SSI beneficiaries with physical disabilities or mental illness were significantly more

likely to say that their health had worsened or stayed the same compared with those with MR/DD.

**Table 2**  
**Health and Functional Status by Type of Disability (percent distribution)**

	Physical Disability	Mental Illness	MR/DD
<b>Current Health Status:<sup>1</sup></b>			**a, **b
Excellent/very good	5.7	2.9	13.3
Good	9.1	10.3	16.1
Fair	30.3	31.1	32.2
Poor	55.0	55.7	38.4
<b>Health Compared to a Year Ago:<sup>1</sup></b>			**a, **b
Better	10.5	9.8	6.4
Same	51.8	47.8	61.5
Worst	37.6	42.5	32.1
<b>ADL Limitations:<sup>1</sup></b>		**a	
None	54.8	53.8	63.7
One	14.6	20.9	16.3
Two or more	30.6	25.2	20.0
<b>IADL Limitations:<sup>1</sup></b>		**a	**a
None	32.1	25.5	25.1
One	22.5	18.5	15.1
Two	12.7	18.7	19.6
Three	12.8	13.6	10.2
Four or more	19.9	23.7	29.9

<sup>1</sup> Percentage distributions sum to 100 within category by column.

\*(\*\*) <sup>a</sup> Significantly different from respondents with physical disability at .05 (.01) level.

\*(\*\*) <sup>b</sup> Significantly different from respondents with mental illness at .05 (.01) level.

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999.

PROGRAMS: final 12b-e

Beneficiaries with physical disability reported significantly more limitations with ADLs: almost one-third were limited in their ability to perform 2 or more such activities compared with one-quarter of those with mental illness and one-fifth of those with MR/DD. By contrast, respondents with mental illness and MR/DD were significantly more likely to report a greater number of limitations in IADLs than did those with physical disabilities.

Almost all beneficiaries reported that they had a usual source of care for their general medical care, regardless of their type of disability (*Table 3*). There were no differences in the type of place they went to, with over one-half of all respondents reporting a doctor's office and

one-third reporting a community health center or other clinic. While the majority of all respondents (90%) reported that they saw the same doctor at this place “always” or “most of the time”, this continuity in provider was significantly higher for those beneficiaries with physical disabilities.

**Table 3**  
**Usual Source of Care by Type of Disability (percent distribution)**

	Physical Disability	Mental Illness	MR/DD
<b>Usual Source of Care (% yes)</b>	97.1	97.8	94.7 <sup>*b</sup>
<b>Type of Usual Source:<sup>1</sup></b>			
Doctor's office	59.8	60.0	59.3
Hospital OPD	5.5	5.8	6.7
Community health center/other clinic	33.1	29.5	29.4
Emergency room	1.0	2.3	3.9
Other	0.7	2.4	0.8
<b>See Same Doctor at Usual Source:<sup>1</sup></b>		*a	*a
Always	66.7	65.3	62.4
Most of time	25.9	22.9	24.4
Sometimes/rarely	7.4	11.9	13.3
<b>Usual Source of Mental Health Care:<sup>2</sup></b>		**a	**a, **b
Percent with	22.9	59.9	31.6

<sup>1</sup> Percentage distributions sum to 100 within category by column.

<sup>2</sup> Excludes those saying they do need mental health care.

\*(\*\*) <sup>a</sup> Significantly different from respondents with physical disability at .05 (.01) level.

\*(\*\*) <sup>b</sup> Significantly different from respondents with mental illness at .05 (.01) level.

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999.

PROGRAMS: final 12b-e

As expected, beneficiaries with mental illness were significantly more likely to have a usual source for mental health care compared with those with other types of disability. However, the percentage with such a source is surprisingly low (60%), given the serious nature of their mental illness.

**Table 4** presents four utilization measures for the past year (doctor visit for general medical care, mental health visit, emergency room visit, and inpatient hospital stay) and two measures for the most recent three months (doctor visit and mental health visit). The top half of the table compares these utilization measures as calculated from the survey responses; the bottom half compares the same measures as constructed from Medicaid claims. While the absolute levels of use may vary, depending on whether survey responses or claims data may use,



they are remarkably similar. Even more important, the patterns across disability groups remain the same, regardless of which source is used for comparison.

**Table 4**  
**Utilization of Services by Type of Disability**

	Physical Disability	Mental Illness	MR/DD	All
<b><u>Survey-Based Measures</u></b>				
<b>In Last 12 Months, Percent with:</b>				
Physician visit	94.3	94.1	86.4	91.9
Mental health visit	22.9	58.2 <sup>**a</sup>	31.2 <sup>**a,**b</sup>	36.4
Overnight hospital stay	30.0	29.3	19.7 <sup>**a,**b</sup>	26.7
ER visit	46.5	56.7 <sup>**a</sup>	43.4 <sup>**b</sup>	48.7
<b>In Last 3 months, percent with:</b>				
Physician visit	84.3	88.4	72.0 <sup>**a,**b</sup>	82.0
Mental health visit	6.7	35.1 <sup>**a</sup>	10.0 <sup>**b</sup>	16.5
<b><u>Claims-Based Measures</u></b>				
<b>In Last 12 Months, Percent with:</b>				
Physician visit	96.3	97.1	91.4 <sup>**a,**b</sup>	95.2
Mental health visit	21.1	50.5 <sup>**a</sup>	21.8 <sup>**b</sup>	30.5
Overnight hospital stay	29.7	27.7	15.5 <sup>**a,**b</sup>	25.1
ER visit		55.9 <sup>**a</sup>	43.8 <sup>**b</sup>	49.7
<b>In Last 3 months, percent with:</b>				
Physician visit	83.6	86.7	73.3 <sup>**a,**b</sup>	81.8
Mental health visit	11.2	33.1 <sup>**a</sup>	12.8 <sup>**b</sup>	18.5

\*(\*\*) <sup>a</sup> Significantly different from respondents with physical disability at .05 (.01) level.

\*(\*\*) <sup>b</sup> Significantly different from respondents with mental illness at .05 (.01) level.

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999, and Medicaid claims.

Although the vast majority of all beneficiaries had seen a physician during the past year, beneficiaries with MR/DD were significantly less likely to have made such a visit. Not surprisingly, beneficiaries with mental illness were significantly more likely to have had a mental health visit than were either those with physical disability or those with MR/DD. (Respondents were MR/DD were also significantly more likely to have had such a visit compared with those with physical disabilities.) Nevertheless, the absolute level of mental health visits is surprisingly low for persons with a mental illness so disabling that they qualified for SSI.

Beneficiaries with MR/DD were less likely to have been admitted to the hospital over the past year than either of the other two groups. Beneficiaries with mental illness were significantly

more likely to have had an emergency room (ER) visit compared with those with physical disability or MR/DD.

Responses for utilization during the past three months mirrored those for 12 months. Again, while the majority of beneficiaries had seen a physician during the past 3 months, those with MR/DD were significantly less likely to have done so. Similarly, while beneficiaries with mental illness were significantly more likely to have made a mental health visit during the past 3 months, absolute levels of use are low, only 35 percent.

Given the severity of their mental illness, we suspect that almost all of these beneficiaries are on some form of psychotropic medication and therefore should be monitored regularly by a psychiatrist or other mental health provider. A failure to recall visits can be ruled out as an explanation, as the claims-based measures completely validate respondents' self-reports (see the bottom half of Table 4).

While the utilization patterns are the same across disability group for both the survey-based and claims-based measures, there are a few differences in levels of use within groups. The appendix tables (*A-1 through A-3*) test for differences between self-reports and claims-based measures for each of the three groups. Levels of agreement were remarkably high across persons with different types of disability. There was no evidence that respondents with MR/DD were any less able to recall utilization, compared with those with physical disability or mental illness. The appendix tables do show, however, that beneficiaries with mental illness and MR/DD underestimate their 12-month physician visits somewhat and overstate their 12-month mental health visits relative to the claims data. State officials in Kentucky report that primary care physicians often provide mental health care in rural areas, including the prescription of psychotropic drugs. These visits would appear in the claims data as routine physician visits, not mental health visits.

*Table 5* shows both survey-based and claims-based measures of unmet need. Respondents were asked if they had needed, but had not received one of two services during the past year: physician visits and mental health visits. SSI beneficiaries with physical disability and mental illness reported significantly more unmet need for physician visits than did those with MR/DD, although absolute levels are high for all groups (18-28%). The two most common reasons given for not receiving the needed visit were transportation problems and being "too busy to get care". Beneficiaries with mental illness were also twice as likely to report unmet need for mental health care: 11.6 percent compared with less than 5 percent of those with physical disabilities or MR/DD.

The percent of beneficiaries with at least one admission during the previous year for an ambulatory care sensitive (ACS) condition is also shown in Table 5. Because total ACS admission rates were relatively low, we were not able to disaggregate rates by individual ACS condition. Beneficiaries with mental illness were significantly more likely to have been hospitalized with an ACS condition during the past year, compared with those with MR/DD.

**Table 5**  
**Unmet Needs for Care by Type of Disability**

	Physical Disability	Mental Illness	MR/DD
<b>Self-Reported Unmet Need (% reporting yes):</b>			
Physician visit	22.4	27.9	18.0 <sup>***b</sup>
Mental health visit	4.7	11.6 <sup>***a</sup>	4.3 <sup>***b</sup>
<b>ACS Admission (% with at least one):</b>	6.4	9.8	4.0 <sup>***b</sup>

\*(\*\*) <sup>a</sup> Significantly different from respondents with physical disability at .05 (.01) level.

\*(\*\*) <sup>b</sup> Significantly different from respondents with mental illness at .05 (.01) level.

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999, and Medicaid claims.

### Regression Findings

Observed differences in utilization and unmet need across disability groups may be due to underlying differences in health and functional status as well as the nature of the disability itself. In order to disentangle these different factors, we estimated a series of logistic regressions. The seven dependent variables included:

- Physician visits, whether the respondent had a physician visit in the past 12 months, whether he/she had a visit in the past 3 months, and unmet need for such visits.
- Mental health visits, whether the respondent had a mental health visit in the past 12 months, whether he/she had a visit in the past 3 months, and unmet need for such visits.
- ACS admission, whether the respondent had a hospitalization for an ACS condition in the past 12 months.

**Table 6** presents the odds ratios for type of disability (mental illness and MR/DD, respectively, with physical disability as the reference group), whether health status is poor or fair, and the number of ADL limitations. Also included in the equations but not shown were variables for age, gender, race, education, physician supply, and an independent measure of travel time based

**Table 6**  
**Odds Ratios for Selected Access Measures**

	Physician Visit			Mental Health Visit			ACS Admission
	12-month	3-month	Unmet Needs	12-month	3-month	Unmet Needs	
SMI	1.10	3.91**	1.39	4.60**	7.13**	2.57**	1.39
MR/DD	0.70	1.54**	0.87	1.65**	1.51	1.01	0.90
Poor Health Status	3.52**	2.00**	3.46**	1.84**	1.16	6.09**	2.51*
Fair Health Status	2.75**	1.30	2.57**	1.23	0.99	4.04**	2.19*
ADL Impairments	1.48**	1.16**	0.99	1.12	1.03	1.02	1.16*

\*\* Significant at .01 level.

\* Significant at .05 level.

NOTE: Additional covariates in regressions included: age, race, gender, education, and provider supply.

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999, and Medicaid claims.

on the terrain of the respondent's county<sup>2</sup>. Health status and ADL limitations were strong predictors of utilization and unmet need. Once we adjust for these (and other) covariates, some of the previously observed differences by type of disability narrow or disappear. For example, there are no longer any differences in unmet need for physician visits or in ACS admissions. Nevertheless, higher rates of use and unmet need for mental health treatment persist for beneficiaries with mental illness. Unmet need for mental health care actually increases relative to beneficiaries with other disabilities, once we adjust for health status and other factors. Beneficiaries with mental illness were two and a half times as likely to report unmet need for mental health care, compared with those with physical disabilities.

## Conclusions

Medicaid beneficiaries with disabilities in rural Kentucky appeared to be receiving adequate primary care for their general medical care needs. Virtually all beneficiaries reported having a usual source of care, typically a physician's office or clinic, and the vast majority had seen a physician in the past 12 months. There were no differences by type of disability in reported unmet need for physician visit or in ACS admission rates, once we control for health status. Nevertheless, absolute levels of unmet need appear quite high, with 23 percent of beneficiaries reporting that they had needed to see a physician during the past year, but did not succeed in getting care. By contrast, only 13 percent of Medicaid beneficiaries with disabilities in New York City reported unmet need for physician care (Long et al., 2002).

Our study does suggest that Medicaid beneficiaries with mental illness in rural Kentucky may not be receiving adequate mental health care. Only 60 percent reported having a usual source of mental health care, and only 58 percent had a mental health visit over the past 12 months. By contrast, 75 percent of New York City Medicaid beneficiaries who were disabled due to mental illness had a usual source of mental health care, and 75 percent reported making a mental health visit over the past year (Long et al., 2002). These low rates of utilization in rural Kentucky were validated using respondents' Medicaid claims.

Beneficiaries with mental illness also were significantly more likely to report unmet need for mental health care compared with beneficiaries with other types of disability, a finding that persisted even after controlling for health status and other factors. However, the actual level of unmet need was considerably lower than that reported for physician care generally: 11.5 percent of beneficiaries with mental illness reported unmet need for mental health care. Similar beneficiaries in New York City reported the same level of unmet need, despite having much higher utilization rates. Given how many beneficiaries with mental illness in rural Kentucky receive no mental health care, it is surprising that their reports of unmet need are not much higher. One explanation is that their expectations for care may be much lower; there is some evidence that residents of rural areas adjust their treatment expectations to the reality of available services (Fox, et al., 1995; Strickland and Strickland, 1996).

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<sup>2</sup> This variable measures how hilly the terrain is in the respondent's county, along with the width and straightness of roads.

More research is needed to better understand access to care for beneficiaries with disabilities, especially those with serious mental illness. In particular, more research is needed using outcomes measures. Our one outcome measure, admission for ACS conditions, may not have been sensitive enough to capture adverse events for persons with serious mental illnesses, like schizophrenia or manic-depression.

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## APPENDIX TABLES



**Table A-1**  
**Validating Health Care Utilization of SSI Beneficiaries with Physical Disabilities**

	Survey (%)	Claims (%)	Percent Agreement
<b>In past year, percent with ...</b>			
Physicians visit	94.3	96.3	92.8
Mental health visit	22.9	21.1	76.7
Emergency room visit	46.5	47.8	81.4
Overnight hospital stay	30.0	29.7	87.1
<b>In past 3 months, percent with ...</b>			
Physicians visit	84.3	82.6	84.7
Mental health visit	6.7	11.2*	92.8

NOTES

\*\* Significantly different from self-reports at the .01 level

\* Significantly different from self-reports at the .05 level

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999, Medicaid claims.

**Table A-2**  
**Validating Health Care Utilization of SSI Beneficiaries with Mental Illness**

	Survey (%)	Claims (%)	Percent Agreement
<b>In past year, percent with ...</b>			
Physicians visit	94.1	97.1*	93.0
Mental health visit	58.2	50.5*	74.5
Emergency room visit	56.7	55.9	75.5
Overnight hospital stay	29.4	27.7	85.0
<b>In past 3 months, percent with ...</b>			
Physicians visit	88.4	86.7	89.1
Mental health visit	35.1	33.1	80.3

NOTES

\*\* Significantly different from self-reports at the .01 level

\* Significantly different from self-reports at the .05 level

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999, Medicaid claims.

**Table A-3**  
**Validating Health Care Utilization of SSI Beneficiaries with MR/DD**

	Survey (%)	Claims (%)	Percent Agreement
<b>In past year, percent with ...</b>			
Physicians visit	86.4	91.4 *	88.7
Mental health visit	31.2	21.8 **	74.1
Emergency room visit	43.4	43.8	80.5
Overnight hospital stay	19.7	15.5	88.6
<b>In past 3 months, percent with ...</b>			
Physicians visit	72.0	73.3	82.9
Mental health visit	10.0	12.8	89.8

NOTES

\*\* Significantly different from self-reports at the .01 level

\* Significantly different from self-reports at the .05 level

SOURCE: Survey of Medicaid SSI beneficiaries in rural Kentucky, 1999, Medicaid changes.