

Poor and Disabled In Rural Kentucky: Access to Care for SSI Adults and Children

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Abstract

In 1995 Kentucky received a waiver from CMS to enroll its Medicaid beneficiaries, including persons with disabilities, into managed care. The state began with the Lexington and Louisville areas and planned to transition managed care into rural regions in the following years. This phase-in of managed care allowed us to plan an evaluation that studied the effect of managed care on persons with disabilities using “pre” and “post” surveys in two rural regions of the state. Kentucky subsequently decided not to implement managed care in any of the other regions of the state. However, by that time the pre-managed care survey had been conducted.

Using the baseline data, we analyzed access to and utilization of health care for SSI recipients and conducted three main analyses. First, we analyzed adults with SSI by type of disability (physical disability, mental illness, mental retardation/developmental disability). Second, we compared adults in the two regions of Kentucky with a similar sample of SSI adult recipients from the 1997 National Health Interview Survey. We then compared adults to children from the two regions in Kentucky. Within Kentucky, SSI recipients generally reported a high level of unmet need and lower than expected utilization of mental health services and physician visits. When we compared rural Kentucky to the US, we found that SSI recipients in rural Kentucky had access to health care services that was as good as or better than the national sample, but that they reported a higher percentage of poor health than the national average. Compared to the adults in Kentucky, children in Kentucky were in better health, had lower levels of unmet need and had expected utilization rates.

1

Introduction

Like many states, Kentucky obtained an 1115 waiver from HCFA (approved in 1995) to enroll its Medicaid beneficiaries into managed care. Prospective managed care enrollees were to include persons receiving SSI because of disabilities. The State chose to implement managed care on a region by region basis, beginning in the more urban parts of the state. Capitated plans began operations in the Louisville and Lexington areas in November 1997. The State then planned to transition the remaining rural areas into the program over the subsequent year or two. Some policymakers and advocates were concerned about how managed care might work in these areas, especially for persons with disabilities.

The phased-in implementation of managed care in Kentucky gave us the opportunity to conduct both “pre” and “post”-managed care surveys of SSI recipients in two rural parts of the study. The baseline survey was fielded in 1999-2000. Since that time, the Kentucky Medicaid program decided not to implement capitated managed care anywhere else in the State. Nevertheless, this baseline survey provides important descriptive data on access to care for persons with disabilities in rural Kentucky.

1.1 Methods

Sample Selection

Because this survey was originally intended to be part of a managed care impact evaluation, the sample was drawn from two of the eight regions the State was planning to use for managed care plan contracting purposes. Known as Regions 4 and 8, both are very rural. Region 4 is located in the south central part of the state. Region 8 is in the eastern part of the state and includes Appalachia. Together, the two regions include 39 counties and contain 43 percent of the non-dual SSI population. Table 1-1 compares selected population characteristics of these two regions with the United States generally. Compared with the U.S. at large, Kentucky residents of Regions 4 and 8 are much more likely to have incomes below the poverty line, to not have graduated from high school, and to have limited access to physicians.

A stratified sample of children and adults aged 18 to 64 was selected from state Medicaid eligibility files. We excluded those SSI recipients dually eligible for Medicare, as well as all residents in nursing homes or other facilities. The strata included region (4 vs. 8), adult vs. child, and (for adults) the type of disability qualifying the individual for SSI (physical disability, mental retardation/developmental disability (MR/DD), mental illness, and unknown¹). The type of disability was obtained from Social Security Administration (SSA) records. Almost two-fifths (39.3%) of our adult sample was

¹ The final sample included 183 adults whose reason for disability was unknown according to SSA records. We asked respondents what disability made them eligible for SSI, and were able to re-classify all but eleven of them. Therefore, there is a difference in adult sample size between Chapter 2 and Chapters 3 and 4.

Table 1-1

Comparison of Sample Kentucky Counties and U.S.

	<u>Sample Kentucky Counties</u>	<u>United States</u>
Percent of Population under 100% of FPL	28	15
Percent Medicaid	23	13
Percent Uninsured	15	16
Percent Graduated from High School	51	75
Population per MD	844	404
Population per Primary Care MD	2,099	1,226
Percent of Population Living in a Health Professional Shortage Area	45	N/A

SOURCE: University of Kentucky Center for Rural Health. County Profiles in Health.
Lexington (KY): Good Samaritan Foundation, Inc., 1997.

eligible because of a physical disability, with the remainder fairly equally divided between MR/DD (29.5%) and mental illness (31.2%).

Data Collection

The survey was conducted by telephone from March through September 1999, using computer-assisted telephone interviewing techniques. A total of 1,342 SSI adults and 437 children responded to the survey with a response rate of 75 percent. Most non-respondents simply could not be located, consistent with other studies that have found

low-income populations to be highly mobile and difficult to track. Once located, almost all eligible respondents participated in the survey; only 2 percent refused to participate. Because it was anticipated that some persons with disabilities might be incapable of completing a telephone interview, survey protocols were developed to identify proxy respondents when needed. Such proxies were needed for 15 percent of the adult sample. (All children were interviewed by proxy, generally the child's mother.) They were used more often for persons with MR/DD (24%) than for persons with other types of disabilities (7%).

Statistical Tests

All observations were weighted to adjust for the probability of selection, including non-response. STATA software was used to adjust variances for the effects of unequal weights and unequal probabilities of selection.

1.2 Overview

Chapter 2 compares our sample of adults with a similar sample of SSI recipients from the 1997 National Health Interview Survey. Chapter 3 conducts a more detailed analysis of our sample of SSI adults, and compares them by type of disability. Finally, Chapter 4 compares our sample of children with the adults.

2

Access to Health Care Services for SSI Adults by Type of Disability

2.1 Characteristics and Health Status

Table 2-1 compares sociodemographic characteristics for survey respondents across the three disability groups. For reference, all tables include a fourth column for the overall sample mean.

The average age of SSI recipients in our non-elderly adult sample was 37 years. Respondents with MR/DD were significantly younger; almost one-half (44%) were under 35 years of age, compared with one-fifth of those with serious mental illness (SMI) and only one-sixth of those with a physical disability. 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. There were no substantial differences by race/ethnicity, with the overwhelming majority of respondents being white. This is consistent with the racial distribution of the population in rural Kentucky generally.

Not surprisingly, respondents with MR/DD were significantly less educated than other SSI respondents. Four-fifths of this group had not completed high school, compared with 73 percent of those with a physical disability and only 66 percent of those with SMI.

Table 2-1

**Sociodemographic Characteristics by Type of Disability
(Percent Distribution)**

	Physical Disability (N=478)	Mental Illness (N=430)	MR/DD (N=423)	All (N=1,331)
Age (years):^a			**	
18-34	15.4	22.7	44.4	26.2
35-44	17.9	27.3	24.2	22.7
45-54	28.9	30.7	18.1	26.3
55-64	37.8	19.3	13.3	24.8
Female (%)	60.9	72.1	50.3 *	61.3
Race:^a				
White	93.8	94.2	92.5	93.6
Black	1.5	1.8	4.2	2.4
Hispanic	0.9	2.2	1.3	1.4
Other	3.8	1.8	2.0	2.6
Education:^a			**	
< 12 years high school	73.4	66.3	81.1	73.3
High school graduate	21.8	27.8	18.0	22.6
Some college	4.9	5.9	0.9	4.1

^a Percentage distributions sum to 100 within category by column.

** Significantly different by type of disability at .01 level.

* Significantly different by type of disability at .05 level.

Significantly different by type of disability at .10 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

The majority of our SSI sample reported that they were currently in fair or poor health, including 87 percent of those with SMI (see Table 2-2). Respondents with MR/DD were significantly healthier, at least based on their self-reports; 13 percent said that they were in excellent or very good health, compared with 5.8 percent of those with a physical disability and only 3.3 percent of those with SMI. Respondents with MR/DD were also more likely to report that their health was the same compared to a year ago. By contrast, those with SMI were more likely to report a worsening in their health status over the past year.

Almost half (45%) of persons with physical or mental disabilities reported a limitation in at least one activity of daily living (ADL). Respondents with MR/DD were significantly less likely to report any functional impairment (only 36%). The majority of all SSI recipients were limited in their ability to perform instrumental activities of daily living (IADL), particularly those with mental illness and MR/DD.

Almost everyone in our SSI sample reported a usual source of general medical care (Table 2-3), although those with MR/DD were slightly less likely to have a usual source (95% vs. 97-98%). There were no differences in the type of usual source, with most respondents relying on either a doctor's office (60%) or clinic (~30%). Federally Qualified Health Centers and other clinics are a traditional source of care in rural Kentucky. About two-thirds of the sample said that they always saw the same doctor at their usual source, although this was somewhat less common for those with MR/DD.

Not surprisingly, beneficiaries with mental illness were significantly more likely to report that they had a usual source of care for mental health treatment. Those with

Table 2-2

**Health and Functional Status by Type of Disability
(Percent Distribution)**

	Physical Disability (N=478)	Mental Illness (N=430)	MR/DD (N=423)	All (N=1,331)
Current Health Status: ^a				**
Excellent	1.4	0.4	4.0	1.8
Very good	4.3	2.9	9.0	5.2
Good	9.1	10.2	16.2	11.5
Fair	30.3	30.9	32.4	31.1
Poor	54.9	55.6	38.5	50.3
Health Compared to a Year Ago: ^a				**
Better	10.6	9.8	6.4	9.1
Same	51.9	47.9	61.4	37.5
Worse	37.5	42.4	32.2	53.4
ADL Limitations: ^a				**
None	54.9	53.6	64.0	57.2
One	14.5	21.3	16.0	17.1
Two	7.9	11.1	9.2	9.3
Three	10.5	8.0	5.1	8.2
Four or more	12.2	6.0	5.7	10.2
IADL Limitations: ^a				**
None	32.5	25.8	25.7	28.4
One	22.3	18.5	15.1	19.0
Two	12.6	18.9	19.2	16.5
Three	12.8	13.4	10.2	12.2
Four or more	19.8	23.4	29.8	24.2

^a Percentage distributions sum to 100 within category by column.

** Significantly different by type of disability at .01 level.

* Significantly different by type of disability at .05 level.

Significantly different by type of disability at .10 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

Table 2-3

**Usual Source of Care, Travel and Waiting Times by Type of Disability
(Percent Distribution)**

	<u>Physical Disability</u> (N=478)	<u>Mental Illness</u> (N=430)	<u>MR/DD</u> (N=423)	<u>All</u> (N=1,331)
Usual Source of Care (% yes)	97.1	97.8	94.6 #	96.6
Type of Usual Source: ^a				
Doctor's office	59.7	60.1	59.1	59.7
Hospital OPD	5.5	5.8	6.7	5.9
Clinic	33.1	29.3	29.5	30.7
Emergency room	0.9	2.3	3.9	2.2
Other	0.8	2.5	0.8	1.5
See Same Doctor at Usual Source: ^a				
			#	
Always	66.6	65.5	62.2	65.0
Most of time	25.9	22.8	24.5	24.5
Sometimes	6.9	8.9	10.9	8.7
Rarely	0.5	2.9	2.4	1.8
Usual Source of Mental Health Care:				
			**	
Percent with	19.1	55.9	28.7	33.5
Percent don't need	16.6	6.4	9.2	9.2
Travel Time to Usual Source: ^a				
			#	
30 minutes or less	71.6	78.2	77.4	75.3
More than 30 minutes	28.4	21.8	22.7	24.7
Waiting Time at Usual Source: ^a				
15 minutes or less	8.9	9.4	13.9	10.4
16-30 minutes	40.5	33.6	35.9	37.0
31-60 minutes	25.3	28.6	25.9	26.5
More than an hour	25.4	28.4	24.3	26.1

^a Percentage distributions sum to 100 within category by column.

** Significantly different by type of disability at .01 level.

* Significantly different by type of disability at .05 level.

Significantly different by type of disability at .10 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

physical disabilities were least likely to have a usual source of mental health care, and were most likely to report that they did not need such care.

The majority of respondents were able to reach their usual source of care within 30 minutes or less. Nevertheless, a substantial minority (25%) reported travel time exceeding an hour, reflecting the geographical isolation of many rural Kentucky residents. Once at their usual source of care, beneficiaries reported very long waits, with one-half reporting waits of more than a half-hour and one-quarter waiting more than one hour.

2.2 Utilization of Health Care Services

There are marked differences in service utilization by type of disability (Table 2-4), but these differences generally are consistent with the service needs associated with different types of disability. Most of the sample reported having seen a physician within the past 12 months, although those with MR/DD were significantly less likely to have made such a visit (86% vs. 94%). While respondents with SMI were significantly more likely to have visited a mental health provider in the past year than respondents with other types of disability, the absolute visit rate (58%) is surprisingly low. SSI recipients with SMI generally suffer from either affective disorders or schizophrenia, diseases that both are treated with psychotropic drugs as well as counseling and psychosocial support. We would have expected most, if not all, persons with SMI to have made a mental health visit.

Table 2-4

Utilization of Services by Type of Disability

	<u>Physical Disability</u> (N=478)	<u>Mental Illness</u> (N=430)	<u>MR/DD</u> (N=423)	<u>All</u> (N=1,331)
Percent with Service During Past 12 Months:				
Physician visit	94.3	94.1	86.4 **	91.9
Mental health visit	22.9	57.9	31.3 **	36.4
ER visit	46.5	56.5	43.6 **	48.7
ER visit for mental health reasons ^a	5.8	23.8	10.9 **	13.5
Inpatient stay	30.1	29.2	19.8 **	26.7
Inpatient stay for psychiatric reasons ^a	4.1	24.6	11.6 **	12.7
Dental visit	47.8	57.3	61.1 **	54.7
Blood pressure check	95.1	96.3	88.8 **	93.6
Pap test (women only)	58.8	62.5	62.4	61.0
Flu shot	29.3	16.8	16.8 **	21.7
Percent with Service During Past 3 Months:				
Physician visit	21.4	50.7	25.8 **	31.8
Visit to specialist ^a	43.8	48.6	36.5 **	43.5
OT/PT/speech therapy	3.7	4.4	3.6	3.9
Home health care	6.8	4.3	3.3 #	5.0
Mental health visit	6.8	35.1	10.1 **	16.5
Substance abuse treatment	0.3	1.3	0.4	0.6

^a Asked of those who reported at least one ER visit/inpatient hospital stay/physician visit.

** Significantly different by type of disability at .01 level.

* Significantly different by type of disability at .05 level.

Significantly different by type of disability at .10 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

Beneficiaries with physical disabilities were significantly less likely to have seen the dentist during the past year: just under half (48%) compared with 57 and 61 percent, respectively, for persons with SMI and MR/DD. The reason for this lower rate is unclear. It is possible that mobility problems prevented some persons with physical disabilities from getting to the dentist's office, but recall that almost all had made it to a physician's office.

About one-half of all sample members had been to the emergency room (ER) in the past year. Beneficiaries with SMI were significantly more likely to have an ER visit and, for those respondents with such a visit, those with SMI were more likely to have made the visit for mental health reasons.

Hospitalization rates were significantly higher for beneficiaries with both physical and mental disabilities, compared with those for MR/DD. Among those with at least one inpatient stay, those with SMI were more likely to have been admitted for psychiatric reasons.

The survey included three measures of preventive services: blood pressure check, Pap test, and flu shot. Respondents with MR/DD were significantly less likely to have had their blood pressure checked during the past year, a finding consistent with their lower rate of physician visits. About 60 percent of women had received a Pap test; there were no differences by type of disability. Persons with physical disabilities were significantly more likely to have received a flu shot, compared with other SSI beneficiaries. This is consistent with clinical guidelines which recommend annual flu shots primarily for the elderly and for persons with chronic medical conditions.

Given their poor health, surprisingly few SSI beneficiaries had seen a physician during the past three months. Only one out of four persons with MR/DD and one out of five with physical disabilities had made a physician visit. Respondents with SMI were twice as likely to have seen a physician, possibly because they included visits to psychiatrists in their response. (Note the relatively high percentage of their physician visits made to specialists.) While persons with SMI were also more likely (as expected) to report a mental health visit during the past three months, the absolute rate is quite low (35%) in light of their disability and poor health status.

There was little utilization of rehabilitation therapies (physical, occupational, or speech therapy) or home health care among any of the three groups of SSI beneficiaries. This is particularly surprising, given the large number who reported ADL limitations.

Finally, almost no one reported any treatment for substance abuse during the past three months. Low utilization rates for this and other services suggests that there may be considerable unmet need for care among SSI recipients in rural Kentucky. We examine this directly in the following section.

2.3 Unmet Need for Care

Table 2-5 shows the percent of each group reporting that they had needed, but had not received, a given service. As a rule, persons with SMI report the highest levels of unmet need, and those with MR/DD the lowest. About one-sixth of persons with SMI (16%) reported an unmet need for medical care or surgery during the past year, compared

Table 2-5

Unmet Need for Care by Type of Disability (%)

	<u>Physical Disability</u> (N=478)	<u>Mental Illness</u> (N=430)	<u>MR/DD</u> (N=423)	<u>All</u> (N=1,331)
Medical Care/Surgery	11.3	16.4	8.4 **	12.0
Physician Visit	22.5	27.8	18.1 **	22.8
Dental Visit	10.0	14.4	8.3 **	10.9
PT/OT/Speech Therapy	4.3	2.7	4.1	3.8
Special Equipment	7.9	5.7	4.3	6.1
Mental Health Treatment	4.7	11.5	4.3 **	6.7
Substance Abuse Treatment	0.0	0.5	0.6	0.3
Prescription Medicine	20.3	28.7	18.9 **	22.5

** Significantly different by type of disability at .01 level.

* Significantly different by type of disability at .05 level.

Significantly different by type of disability at .10 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

with 11 percent of those with physical disabilities and only 8 percent of those with MR/DD. Levels of unmet need were twice as high for physicians' visits, with over one-quarter of beneficiaries with SMI stating that they had not received a needed doctor's visit during the past year. The two most common reasons given for not receiving the needed visit were transportation problems and being "too busy to get care". Other frequently cited reasons were: couldn't get an appointment, "don't like to go, afraid", and physical barriers.

Persons with SMI also reported higher rates of unmet need for dental care, compared with the other two groups. Overall, however, reported unmet dental need was lower than anticipated, given that our site visits in rural Kentucky had indicated that limited dentist participation in Medicaid was a major problem.

There was relatively little reported unmet need for those services expected to be of particular importance to persons with disabilities: rehabilitative therapies and special equipment.

Unmet need for mental health treatment was highest for the group that should need this care the most: persons with SMI. Their level of unmet need appears lower than expected, given their low mental health visit rates. Either persons with SMI in rural Kentucky truly do not need additional mental health services, or they do not recognize that they need this care.

Unmet need for substance abuse treatment is almost non-existent. While somewhat surprising, this is consistent with findings from our supplemental survey of SSI beneficiaries with schizophrenia.¹ Respondents in that survey were administered the CAGE substance abuse screening questions;² almost no one qualified as a potential substance abuser based on that instrument.

Finally, unmet need for prescription medicine is quite high, particularly among persons with SMI where 29 percent report that they did not receive a needed drug

¹ For more information about the sampling methodology, please see: Mitchell JB, Hoover S: "Access to Care for Medicaid Beneficiaries with Schizophrenia: A Study in Rural Kentucky" CMS Contract No. 500-95-0040.

² CAGE screening questions pertain to alcohol abuse.

(compared with 20 percent of those with physical disabilities and 19 percent of those with MR/DD). The most commonly cited reasons for this unmet need was that Medicaid would not approve, or the physician would not prescribe the needed medicine. Based on their verbatim responses, it appears that in many of these cases, the individual was denied the drug because of concerns about addiction or abuse.

2.4 Satisfaction with Care

Survey respondents were asked to rate their satisfaction with a number of dimensions of their medical care (Table 2-6). Almost one-half of beneficiaries rate the quality of their medical care as excellent or very good, but this rating was significantly lower for those with MR/DD. Beneficiaries with MR/DD were somewhat more satisfied with how easily they could find a doctor who accepted Medicaid, however.

About one-third of survey respondents rated their ability to get care from specialists as excellent or very good. Differences by type of disability in this rating reflect differences in the number reporting that they had not needed to seek specialty care. Satisfaction with getting care in emergencies was also relatively high, with the majority of respondents rating this as “good” or higher.

Many respondents did not rate their ability to get mental health care because they had not needed it, including almost half of those with physical disabilities and a surprising 14 percent of those with SMI. The vast majority of persons with SMI rated the ease of getting mental health care as good or higher.

Table 2-6

Satisfaction with Care by Type of Disability
(Percent Distribution)

	<u>Physical Disability</u> (N=478)	<u>Mental Illness</u> (N=430)	<u>MR/DD</u> (N=423)	<u>All</u> (N=1,331)
Quality of Medical Care:^a				**
Excellent	25.9	21.1	18.2	22.2
Very good	20.3	25.9	20.2	22.0
Good	39.2	33.5	45.4	39.2
Fair	13.1	16.4	11.1	13.6
Poor	1.5	3.2	5.0	3.1
Ease of Finding Doctor to Accept Medicaid:^a				*
Excellent	21.9	17.5	20.2	20.0
Very good	17.9	21.7	21.4	20.1
Good	41.8	38.6	42.7	41.0
Fair	12.6	10.5	8.3	10.7
Poor	5.8	11.7	7.0	8.0
Ease of Getting Care from Specialists:^a				
Excellent	20.1	15.0	12.6	16.3
Very good	15.3	19.0	15.1	16.5
Good	36.9	37.5	42.2	38.6
Fair	12.3	15.0	11.1	12.9
Poor	5.1	6.8	5.7	5.8
Ease of Getting Care in Emergencies:^a				
Excellent	15.4	16.0	12.7	14.9
Very good	16.4	16.8	19.8	17.5
Good	39.6	37.3	36.8	38.1
Fair	15.4	17.9	14.0	15.8
Poor	8.0	6.9	9.5	8.0
Ease of Getting Mental Health Care:^a				
Excellent	6.8	18.2	9.8	11.4
Very good	8.9	17.7	14.5	13.4
Good	25.5	33.6	35.3	30.9
Fair	7.3	7.6	8.2	7.6
Poor	4.6	8.7	5.2	6.1
Language Difficulties with Doctor:^a				*
Always	5.7	2.7	6.2	4.9
Most of the time	3.5	6.8	5.5	5.1
Sometimes	9.8	13.7	15.2	12.6
Rarely	81.0	76.8	73.1	77.4

^a Percentage distributions sum to 100 within category by column.

** Significantly different by type of disability at .01 level.

* Significantly different by type of disability at .05 level.

Significantly different by type of disability at .10 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

Finally, the survey asked respondents how often they had difficulties speaking with, or understanding, their physician because they spoke different languages. In the rural regions of Kentucky, many of the physicians are foreign medical graduates who speak English as a second language. The majority of beneficiaries reported that they had rarely had language difficulties, but persons with MR/DD were more likely to report such problems. This may be because persons with MR/DD are more likely to have cognitive limitations and not be able to understand as well.

2.5 Regression Results

In the preceding sections, we saw that utilization and unmet need often varied significantly by type of disability. Some of these differences may be attributable to the disability itself, but others may reflect differences in the distribution of health or functional status *within* disability type. We estimated logistic regressions for many of the utilization and unmet need measures. Table 2-7 presents the odds ratios for selected variables: dummy variables for persons with SMI and MR/DD respectively (persons with physical disabilities are the reference group), dummy variables for whether self-reported health status is poor or fair, respectively, and the number of ADL limitations. Also included in the equations but not shown were variables capturing age, sex, race, education, and provider supply.

Health status and ADL limitations were generally strong predictors of both utilization and unmet need. Once we included these (and other) covariates, many previously observed differences by type of disability narrowed or disappeared altogether, e.g., lower rates of 12-month physician visits and hospital stays by persons with MR/DD.

Higher rates of use and unmet need for persons with SMI generally persisted, however, even after adjusting for these factors. Compared with those with physical disabilities, beneficiaries with SMI reported higher rates of 3-month physician visits, both 12- and 3-month mental health visits, and ER visits. (It is important to keep in mind that, while their physician and mental health visit rates are higher than those for others, the absolute levels of use are low for all respondents.) They also reported higher levels of unmet need for mental health, physician visits, dental visits, and prescription medicine (although only mental health was significant at conventional levels). This unmet need may explain their relatively high use of the emergency room.

2.6 Conclusions

Many of the differences in utilization by type of disability can be explained by the needs of the underlying condition or by the beneficiary's health and functional status. Nevertheless, SSI recipients in rural Kentucky report greater unmet need for many services, and report lower than expected utilization of mental health services. Furthermore, regardless of disability type, all beneficiaries report very limited physician contact during the three months preceding the interview. Further research is needed to compare the experience of these SSI respondents with those in other states.

3

Comparison of Kentucky with U.S. Adults on SSI

Because our sample is limited to 39 counties in rural Kentucky, we have no context for readily evaluating their access to care. For this reason, we wanted to compare them with a national sample of SSI recipients. Use of a national sample provides a benchmark for assessing whether Kentucky SSI recipients are faring better or worse than SSI recipients generally.

3.1 Methods

We identified a comparison group from the 1997 National Health Interview Survey (NHIS). The NHIS is an annual survey of the civilian household population of the United States conducted by the National Center for Health Statistics using computer-assisted personal interviewing (CAPI).¹ Over 36,000 adults were interviewed with a response rate of 80 percent. From this sample, we identified all persons between the ages of 18 and 64 receiving SSI and Medicaid and who did not have Medicare. The final sample size was 568.

Both the Kentucky and NHIS survey instruments collected a vast array of information on health care utilization. In the text that follows, we present findings for those measures that the two shared in common. We note those instances in which

¹ Centers for Disease Control, National Center for Health Statistics: *National Health Interview Survey: Description*. Accessed at <http://www.cdc.gov/nchs/about/major/nhis/hisdesc.htm> on 16 April 01.

question wording differed between the two. Chi-square tests were used to determine the statistical significance of all variables, when comparing Kentucky respondents with their counterparts from the NHIS. Unfortunately, it was not possible to pool the two surveys, because of the difficulties inherent in re-weighting national and sub-state samples.

3.2 Results

Table 3-1 compares sociodemographic characteristics of our Kentucky SSI sample with the SSI respondents in the NHIS. SSI recipients in our Kentucky sample were significantly older; over one-half (51.1%) were aged 45 years or more, compared with 42 percent nationally. There were no differences in the gender distribution, with the majority being women (~60%). SSI recipients in our Kentucky sample were significantly more likely to be white, compared with those nationally, a fact which simply reflects the underlying racial distribution in rural Kentucky. Kentucky SSI recipients were also significantly less well educated, with only one-quarter having graduated from high school (26.7%), compared with almost one-half of SSI recipients nationally (44.8%). As noted earlier in Table 3-1, this is consistent with the respective adult populations of these areas in general.

Table 3-1

**Sociodemographic Characteristics of SSI Recipients in
Rural Kentucky vs. the U.S.
(Percent Distribution)**

	Rural Kentucky (N=1,342)	United States (N=568)
<u>Age:</u> ^a	*	
18-34	26.2	30.7
35-44	22.7	27.2
45-54	26.3	22.1
55-64	24.8	20.1
<u>Female</u>	61.3	60.4
<u>Race:</u> ^a	*	
White	93.6	56.9
Black	2.4	27.1
Hispanic	1.4	12.6
Other/Unknown	2.6	3.4
<u>Education:</u> ^a	*	
Less than 12 years	73.3	55.2
High school graduate	22.6	25.7
Some college	4.1	19.1

^a Percentages sum to 100 by column.

* Significantly different from SSI recipients nationally at the .05 level.

SOURCES: Survey of SSI recipients in 39 rural Kentucky counties, 1999.
National Health Interview Survey, 1997.

SSI adults in rural Kentucky were in significantly poorer health than those in the U.S. as a whole (see Table 3-2). Those in Kentucky were more than twice as likely to rate their health as “poor” on the traditional five-point scale, 50 percent compared with only 19 percent of the national sample. Kentucky respondents were also significantly more likely to report that their health had gotten worse over the past year, 37.5 percent versus 22.6 percent of NHIS respondents. In addition to their poor health status, rural Kentucky SSI recipients were more functionally impaired. Almost one-half of SSI adults in Kentucky had at least one limitation in their activities of daily living, or ADL (42.8%), while fewer than one-tenth of SSI recipients nationally reported any limitation (7.1%). Similarly, the vast majority of Kentucky respondents (76%) reported that they needed assistance with at least one instrumental activity of daily living (IADL), while only one-fifth of the national sample (21.5%) needed such help.

The vast majority of SSI recipients report having a usual source of medical care (see Table 3-3), but the numbers are even higher for those respondents in rural Kentucky (96.6%) than for those nationally (88.3%). For those with a usual source, there were no differences between the two samples in the type of provider. The majority went to a physician’s office for care (60%), and very few relied on the hospital emergency room as their usual source of care (2-3%).

Respondents in both surveys were asked about their utilization of selected health care services over the past 12 months. As shown in Table 3-3, SSI adults in rural Kentucky were as likely, and often more likely, to have used services during the past year, compared with their counterparts nationally. Almost all respondents from both surveys

Table 3-2

**Health and Functional Status for SSI Recipients in Rural Kentucky vs.the U.S.
(Percent Distribution)**

	<u>Rural Kentucky</u> (N=1,342)	<u>United States</u> (N=568)
<u>Health Status:</u> ^a	*	
Excellent	1.8	6.3
Very Good	5.2	17.6
Good	11.5	25.1
Fair	31.1	31.5
Poor	50.3	19.2
<u>Health Compared to a Year Ago:</u> ^a	*	
Better	9.1	18.2
Same	53.5	59.2
Worse	37.5	22.6
<u>One or More ADL Limitations</u>	42.8*	7.1
<u>One or More IADL Limitations</u>	76.0*	21.5

^a Percentages sum to 100 by column.

* Significantly different from SSI recipients nationally at the .05 level.

SOURCES: Survey of SSI recipients in 39 rural Kentucky counties, 1999.
National Health Interview Survey, 1997.

Table 3-3

**Usual Source of Care and Utilization of Services
(Percent Distribution)**

	<u>Rural Kentucky</u> (N=1,342)	<u>United States</u> (N=568)
<u>Usual Source of Care</u> (% yes)	96.6 *	88.2
<u>Type of Usual Source</u> (% for those reporting a usual source): ^a		
Doctor's office	59.7	59.5
Clinic	30.9	31.8
Hospital OPD	5.9	5.6
Emergency room	2.2	3.1
<u>Utilization During Past Year</u> (percent having any):		
Inpatient hospital stay	26.2 *	20.8
ER visit	48.7 *	39.2
Physician visit	91.9	90.1
Mental health visit	36.4 *	24.0
Dental visit	54.7 *	44.6
Flu shot	21.7	24.0

^a Percentages sum to 100 by column.

* Significantly different from SSI recipients nationally at the .05 level.

SOURCES: Survey of SSI recipients in 39 rural Kentucky counties, 1999.
National Health Interview Survey, 1997.

had visited a physician during the past year (90%). SSI adults in Kentucky were significantly more likely to have been hospitalized, to have gone to the ER, to have gone to a mental health provider, and to have seen a dentist, compared with SSI adults nationally. There were no differences in the frequency of flu shots between the two groups.

As we saw earlier in Table 3-2, the Kentucky respondents report far worse health and greater functional limitations. This could well explain their higher rates of use for some services. At the same time, they may not receive all the services they need. Both Kentucky sample members and NHIS respondents were asked if there was ever a time in the past year when they had needed a health care service but did not get it. Table 2-4 compares reported unmet need for those services the two surveys had in common. There was one important difference in the way the questions were asked. The NHIS added the phrase “a service you did not get because you couldn’t afford it”. However, the Kentucky survey followed up with a second question, asking why the respondent did not receive the service. This allowed us to create a response category that was more comparable to NHIS. We show both the percent of all Kentucky respondents who did not receive the service, as well as the subset not receiving the service because they could not afford it.

SSI recipients in our Kentucky sample were as likely as those in the U.S. as a whole to report unmet need for medical care or surgery, less likely to report unmet need for dental care, and more likely to forego needed mental health treatment or prescription medicine. When restricted to those Kentucky respondents who cited cost as the reason,

Table 3-4

Unmet Need for Services During Past Year (percent reporting yes)

	Rural Kentucky		United States
	<u>Did Not Receive, Any Reason</u>	<u>Did Not Receive, Could Not Afford</u>	<u>Did Not Receive, Could Not Afford</u>
Medical care/surgery	12.0	6.3*	12.3
Dental care	10.9*	.04*	15.5
Mental health treatment	6.7*	.03*	4.0
Prescription medicine	22.5*	3.2*	12.6

* Significantly different from SSI recipients nationally at the .05 level.

SOURCES: Survey of SSI recipients in 39 rural Kentucky counties, 1999.
National Health Interview Survey, 1997.

Kentucky SSI recipients were far less likely to report unmet need than were those in the NHIS. This restricted comparison may be an underestimate of the true number of Kentucky respondents who could not get needed care due to costs. Some respondents cited reasons, such as “could not find a provider who accepted Medicaid” or “Medicaid did not approve care”. Implicit, in these instances, would seem to be the respondent’s perception that they could not afford to pay for the care on their own.

The relatively high proportion of Kentucky SSI recipients who did not receive needed prescription medicine (22.5%) is surprising. Relatively few of these recipients cited cost as a factor, so what accounts for such high unmet need? The most commonly cited reasons were that Medicaid would not approve, or the physician would not

prescribe, the drug in question. Based on verbatim responses recorded as part of the interview, it appears that in many of these cases, the individual was denied the prescription because of addiction or drug abuse. In the Kentucky Medicaid program, known drug abusers are locked into a single prescribing physician and a single pharmacy in order to prevent “shopping”. State officials report that rates of such “lock-in” are particularly high in Appalachia, generally due to abuse of prescription drugs, such as painkillers and tranquilizers. According to the survey data, the rates of unmet need were higher in Region 8 (24.0%) compared to Region 4 (19.1%), although the difference was not significant.

3.3 Conclusions

Based on those responses they shared in common, SSI recipients in rural Kentucky appear to enjoy access to health care services that is as good as or better than that of a national sample of SSI recipients. At the same time, the Kentucky sample respondents reported significantly poorer health status, suggesting that their need for medical care may also be greater. This could explain their higher rates of hospitalization and emergency room use, compared with the national sample. These higher rates might also suggest that Kentucky respondents are not getting access to timely and appropriate outpatient care that might prevent hospitalization. Unfortunately, the only physician visit measure the two surveys had in common was whether or not the respondent had seen a physician in the past 12 months. The vast majority (over 90%) of both samples had seen a physician at least once, but we have no measures of the number of visits or visit intensity.

The Kentucky survey also asked about three-month physician visits, and only one-third of respondents (31.2%) reported making at least one visit during this time period. Given their poor health and functional status, this visit rate seems quite low, but we have no benchmark to measure it against.

We were unable to compare the two samples, while controlling for type of disability. (This information was not available on the NHIS.) Of particular concern is access to mental health services for persons with serious mental illness. Only one-third of Kentucky SSI recipients with serious mental illness had seen a mental health provider during the previous three months, and just over one-half (57.9%) had seen such a provider in the past year. Again, we have no way of determining whether this rate is low relative to other persons with serious mental illness.

At the same time the Kentucky survey was conducted, SSI recipients in New York City and Westchester County were surveyed under this project, using the identical instrument. Under two other 1115 waiver evaluations, similar (but not identical) surveys of SSI recipients were conducted in Oregon and in Tennessee. In future work, we plan to pool these four surveys and compare utilization, access, and satisfaction, after adjusting for health status and other factors.

4

Comparing SSI Children and Adults from Rural Kentucky

4.1 Sociodemographic Characteristics and Health Status

Table 4-1 compares SSI adults and SSI children¹ in terms of available and relevant sociodemographic characteristics. Over half of the adult respondents were over 45 years of age, while the middle of the age distribution for children fell at 10 years of age. The gender distribution of SSI adult and children differed significantly. Although almost two thirds of the adult respondents were female (61.3%), the survey of children did not reflect the same pattern. Just over one third of the children surveyed (36.1%) were female. Slightly more of the children who responded were nonwhite relative to the adult respondents (11% versus 6.5%). The low numbers of nonwhite respondents in both adult and child categories reflect the underlying racial distribution in rural Kentucky. For both adult and child respondents, approximately half receive food stamps.

Health status comparisons between SSI children and adults, shown in Table 4-2, are revealing. Self-reports² of health status show that the distribution of reports from poor to excellent differs significantly. More than a fifth (20.7%) of children rate their health as very good or excellent, compared to only 7 percent of adults. Over four fifths (81.4%)

¹ Though children are referred to as respondents, technically their responses were recorded through proxies.

² Again, these are proxy reports for children.

Table 4-1

Sociodemographic Characteristics of Adults and Children on SSI

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Median age (years)	45*	10
Percent Female	61.3*	36.1
Percent Nonwhite	6.5*	11.0
Percent Receiving food stamps	50.9	49.7

* Significantly different at the 0.05 level

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

of adults rate their health as fair or poor, compared to a little over half of the children (54.4%). In comparisons to their health a year ago, the same pattern persists. Over 90 percent of children report their health as the same or better than a year ago, while under half of the adult population feels the same way (46.6%).

The resilience of the young as well as different reasons for SSI eligibility may contribute to the marked differences in health status reports. Slightly more children³ report being free of limitations in performing their activities of daily living. Roughly one third of both adults and children are eligible for SSI because of physical disability. The

³ For most ADL questions, only children over five years of age were asked to respond.

Table 4-2
Health Status Comparison
(Percent Distribution)

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Self-reported health status *		
Excellent	1.8	7.7
Very good	5.2	13.0
Good	11.5	25.0
Fair	31.1	38.1
Poor	50.3	16.3
Compared to one year ago *		
Better	9.1	20.3
Same	37.5	70.5
Worse	53.5	9.1
No ADL limitations	57.2	63.8
Reason eligible for SSI *		
Mental illness	39.3	10.0
MR/DD	29.5	49.0
Physical disability	31.2	32.4

* Significantly different at the 0.05 level

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

similarities end with physical disability, however. Almost 40 percent of adults are SSI eligible because of mental illness, compared with only one tenth of the children (10%). Close to double the number of children are SSI eligible because of mental retardation or developmental delay. Nearly half of the responding children have MR/DD problems (49%), compared to 29.5 percent of adults. For the children responding, just fewer than 9 percent report “other” reasons for being SSI eligible.

4.2 Utilization of Health Care Services

Table 4-3 presents descriptive statistics related to child and adult usual sources of health care. Children more often report having a usual source of health care than do adults, but in both cases the rates are over 96 percent. There are small differences in the places that adults and children seek their care. Adults report using private offices and hospital emergency rooms as usual sources of care more than do children. Children seek their care at clinics, health centers, outpatient departments or rehabilitation facilities more often than do adults. Over 95 percent of both adults and children report seeing a physician at their usual place of care.

Separate questions were asked about a usual source of care for mental health care. There were broad similarities between child and adult responses. For both children and adults, just over one tenth of the respondents reported not needing mental health care. One third reported having a usual source of mental health care. Of these respondents, more than half reported the Hospital ER as their usual source of mental health care which might reflect a lack of access to mental health care. Almost 30 percent of adults and 22.7 percent of children reported using clinics and health centers as their usual sources of mental health care. The remaining respondents are split between private offices and outpatient departments, with more children reporting use of the former (14.7% versus 6.3%), and more adults reporting use of the latter (11.3% versus 7.3%).

Table 4-3

**Adult versus Child Health Care Utilization Patterns: Usual Source of Care
(Percent Distribution)**

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Usual Source of Care (% yes)	96.6 *	99.2
Type of Usual Source: ^a		
Private office	59.7	55.0
Clinic/Health Center	30.9	34.4
Hospital ER	2.2	0.5
Outpatient Department	5.9	8.3
Rehab Hospital or Other	1.3	1.8
See same doctor at usual source		
Always	64.6	58.1
Most of the time	24.5	28.9
Sometimes	8.9	27.2
Rarely	1.9	3.2
Usual Source of Mental Health Care:		
Percent with	33.5	35.2
Percent don't need	11.3	12.5
Travel Time to Usual Source:		
30 minutes or less	75.3	73.9
More than 31 minutes	24.7	26.1
Waiting Time at Usual Source:		
15 minutes or less	10.4	13.7
16-30 minutes	37	43.9
31-60 minutes	26.5	24.7
More than one hour	26.1	17.7
Percent reporting same USC for physical and mental health	24.2 *	14.6
Percent always or mostly having difficulty understanding MD	10.0	7.8
Percent able to get same or next day appointment with USC	71.8 *	84.2

* Significantly different at .05 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

Almost one quarter of adult respondents with a usual source of care report the same usual source of care for both general and mental health. The corresponding number for children is significantly lower, at 14.6 percent. Children report always or mostly seeing the same provider at their usual source of care with more frequency (87.5%) although close to four fifths of adults always or mostly see the same provider too. It appears that continuity of care for routine ailments, among those with a usual source of care, is reasonably good. With so few reporting a usual source of mental health care and the emergency being used as a usual source of care for many of those with a usual source of care, continuity of mental health care appears to be more of an issue.

Recent utilization patterns of adults and children are presented in Table 4-4. Using the past year as a frame of reference, visit rates for children and adults are comparable for visits to doctors and emergency rooms, for physical and mental health reasons. Over 90 percent of respondents have seen a doctor for general problems, over one third have seen one for mental health care, almost half have been to the emergency room for a general health reason, and 13 percent have been to the ER for mental health reasons. Differences emerge for hospital stays. Adults report more frequent stays for general health reasons (26.7% versus 19.1%) while children report more psychiatric inpatient stays than do adults (20.6% to 12.7%).

Patterns for the past three months of service utilization reveal more differences.⁴ Almost 50 percent more of the children saw a doctor in the past three months relative to adults. This might reflect the relative stability of adult health, or poorer access for adults.

⁴ The analyses for children were not done by age because the sample size was too small.

Table 4-4

**Recent Utilization Patterns
(Percent Distribution)**

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Percent with Service During Past 12 Months:		
Physician visit	91.9	93.0
Mental health visit	36.4	35.8
ER visit	48.7	45.5
ER visit for mental health reasons ^a	13.5	13.1
Inpatient stay	26.7 *	19.1
Inpatient stay for psychiatric reasons ^a	12.7	20.6
Percent with Service During Past 3 Months:		
Physician visit	31.8 *	81.2
Alcohol or Drug Counselling	0.6	0.4
Mental health visit	16.5 *	21.6
PT/OT/speech therapy	3.9 *	34.9
Home care	5.0	4.7
Preventive care		
Last dental visit within past year	53.7 *	64.5
MMR immunization before 18 months		97.5
Last preventive care visit within past year		91.9

* Significantly different at .05 level.

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

Children reported recent physical or occupational therapy much more often than adults (34.9% versus 3.9%). This is probably because of the larger proportion of the child respondents that have MR/DD. More children reported seeing a mental health provider than did adults (21.6% versus 16.5%). Very small numbers reported alcohol and substance abuse counseling (under 1%) and close to 5 percent of adults and children reported using home healthcare.

4.3 Unmet Need for Care

The children and adult responses about unmet need for medical care are presented in Table 4-5. In general, adults appear to have more unmet medical needs than do children. Over one fifth of adults report unmet need in terms of physicians and prescriptions. Over one tenth of adults report unmet medical and dental needs. The main issues for children are access to prescriptions (11.8%), to therapy (8.9%) and to dental care (8.5%). High rates of abuse of prescription drugs in Appalachia, and the resulting lock-in to one prescribing physician may contribute to high rates of unmet prescription needs for adults, but it is not clear whether it contributes as well to high rates of child unmet prescription need.

Table 4-5

Unmet Need for Care
(percentage reporting yes)

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Unmet medical care	12.0	7.8
Unmet dental care	10.9	8.5
Unmet physician need	22.8*	6.6
Unmet therapy	3.8*	8.9
Unmet drug/alcohol help	0.3	0.0
Unmet mental health	6.7	6.7
Unmet medical equipment need	6.1	6.3
Unmet prescription need	22.5*	11.8

* Significantly different at the 0.05 level

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

4.4 Satisfaction with Care

The survey respondents address several dimensions of quality of care including overall quality, access to providers, case management assistance and whether they have enough say in their care. Overall quality ratings, presented in Table 4-6, are higher for children, with 52.5 percent reporting their care as very good or excellent as opposed to 44.2 percent of adults who do the same. More than half the adults report their care as poor, fair or good (55.1%) as opposed to 47.5 percent of children. This may relate to the lower numbers of children reporting unmet need, among other factors, although differences are not significant.

Table 4-6

**Overall Quality of Medical Care
(Percent Distribution)**

<u>Quality of Medical Care</u>	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Poor	3.1	2.7
Fair	13.6	9.7
Good	39.2	35.2
Very good	22.0	25.0
Excellent	22.2	27.5

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

Respondents were asked about the ease of getting care from a Medicaid physician, specialist, emergency room, and a mental health professional. Table 4-7 presents their responses. In all cases, children reported that care was easily obtained (very good or excellent ease of getting care) more frequently than did adults. The difference was largest for emergency care (43.9% versus 32.4% for adults) and smallest for mental health care (27.8% versus 24.8% for adults). Except in the case of mental health care, one third or more of the respondents report that it is very easy to get care. Generally another third of respondents rate the ease of getting care as good, which leaves a third or more who think that the ease of getting care is fair or poor. While this is perhaps indicative of a very rural setting, it appears problematic, especially for such a sick population.

Table 4-8 presents responses to questions about whether the respondent has any help keeping in touch with doctors or arranging nonmedical services. More than half of adult respondents report that someone else is also in touch with their doctors, and almost

Table 4-7
Access to Care
(Percent Distribution)

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Ease of finding Medicaid doctor		
Poor	8.0	8.3
Fair	10.7	8.2
Good	41.0	35.3
Very good	20.1	21.9
Excellent	20.0	26.4
Ease of getting care from a specialist		
Poor	5.8	4.9
Fair	12.9	12.5
Good	38.6	36.0
Very good	16.5	20.0
Excellent	16.4	19.5
Don't need	9.9	7.0
Ease of getting care in an emergency*		
Poor	8.0	7.1
Fair	15.8	11.9
Good	38.1	35.7
Very good	17.5	20.2
Excellent	14.9	22.9
Don't need	5.7	2.2
Ease of getting mental health care		
Poor	6.1	4.9
Fair	7.6	8.3
Good	30.9	29.4
Very good	13.4	14.4
Excellent	11.4	13.4
Don't need	30.6	29.7

*Significantly different at the 0.05 level

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

half (47%) report that someone helps them to arrange nonmedical services. The corresponding proportions for child respondents are lower, one third having someone else in touch with doctors and one quarter having help arranging nonmedical services. This most probably reflects the fact that the respondent for a child is already a caregiver/proxy.

The last question in Table 4-8 asks respondents whether they feel they have enough say in their medical decisions, and 90 percent or slightly more say that they do.

Table 4-8
Assistance with Case Management
(percentage reporting yes)

	<u>Adults</u> (N=1,342)	<u>Children</u> (N=437)
Does anyone else also keep in touch with doctors?	54.9*	32.3
Does anyone else help arrange nonmedical services?	47.0*	23.9
Do you have enough say in medical decisions?	90.0*	92.6

*Significantly different at the 0.05 level

SOURCE: Survey of SSI recipients in 39 rural Kentucky counties, 1999.

4.5 Conclusions

It appears that SSI eligible children in rural Kentucky have slightly better health status, access to care, and satisfaction with their services than do their adult counterparts. Children have higher self-reported health status, a greater tendency to report better or the same health as a year ago, and fewer ADL limitations. Unmet need measures are also lower for children, with the exception of need for therapy, which is likely driven by the large group of children who have high therapy needs due to MR/DD issues. Health care

utilization rates for the past year and the past three months did not show evidence of being low, and virtually all children report having a usual source of care. Almost 90 percent of children responded that they always or mostly saw the same provider, and 84 percent were able to get an appointment the same or the next day.

Adults do not fare as well, perhaps due to the higher numbers with mental illness. Mental health care appears to be the least satisfying part of care for adults. There is some evidence of low utilization of physicians and mental health providers that leads to higher utilization of hospital emergency rooms. Continuity of care is important for adults with disabilities, especially those with mental illness. It is possible, however, that a small group of adults with serious mental issues and or prescription drug issues are driving the results disproportionately. There are more children than adults who required psychiatric hospitalization in the past year. Given that 40 percent of adult respondents and only 10 percent of children report mental illness, this is a striking finding. Further work will address the currently hidden heterogeneity in both adults and children to a greater degree.

Multivariate analysis may be helpful in sorting out some discrepancies. For example, despite significant unmet need for adult physician visits and prescriptions, and indications of low mental health utilization, overall quality ratings for adults are quite high. Adults and children also report a high level of satisfaction with their involvement in their care. The idea that access to physicians is limited because of the lack of supply in such rural areas appears to be contradicted by the fact that children report few problems with access. Adults with MR/DD appear to have the hardest time locating help, while their younger counterparts appear to be well-served. Looking at utilization patterns by type of disability would yield a more nuanced understanding.