Although disabled individuals account for a disproportionate share of Medicaid expenditures, little is known about their health care needs and experiences. This article explores differences in access and use among key disability subgroups—adults with physical disabilities, mental illness, and mental retardation/developmental disabilities (MR/DD). We find that disabled Medicaid beneficiaries with mental illness and those with greater health and functional limitations face more difficulties in obtaining care. This suggests a need for changes in the system of care under Medicaid, including targeting efforts to improve access to individuals with specific types of disabilities.

INTRODUCTION

Disabled individuals account for about one-sixth of the Medicaid caseload but more than one-third of program expenditures (Kaiser Commission on Medicaid and the Uninsured, 2001). Yet, little is known about the health needs of disabled Medicaid beneficiaries and their experiences under the Medicaid Program (Davis and O’Brien 1996; Hagglund et al., 1999; Meyer and Zeller, 1999; Hill and Wooldridge 2000; Center for Health Care Strategies Inc., 2000; Shalala, 2000). State administrative data provide little or no information on a beneficiary’s disabling condition, health care needs, and barriers to care. Surveys of the disabled Medicaid population can provide more in-depth information on how the disabled are faring, however, such surveys are rare. Until very recently, disabled Medicaid enrollees have not been the central subject of a major survey.

With State’s growing efforts to move disabled Medicaid beneficiaries into managed care, interest in better understanding the needs and experiences of those individuals has escalated. Accordingly, CMS recently funded a survey that focuses on the health and health care experiences of disabled Medicaid beneficiaries in New York City. New York was selected for the study because of plans by the State to implement mandatory capitated managed care for disabled Medicaid beneficiaries in the future. Thus, in addition to providing important new information about the experiences of disabled Medicaid beneficiaries, the survey provides a baseline for a future evaluation of the impacts of the shift to mandatory managed care on disabled beneficiaries. In this article, we use that survey data to explore differences in access to and use of care among key subgroups of the disabled Medicaid population—adults with physical disabilities, mental illness, and MR/DD.

We address three related questions:

• Does access and use under Medicaid vary for individuals with physical disabilities, mental illness, and MR/DD?

• Can the differences in their health care experiences be explained by their differing health care needs or, alternatively, are there persistent differences in access to care under Medicaid for some groups of disabled persons?
• Beyond disabling condition, what other characteristics of the disabled population (e.g., health status, functional limitations) predict greater difficulties with accessing care under the Medicaid Program?

We focus on the health care experiences of non-aged adults who are eligible for Medicaid by virtue of their receipt of Supplemental Security Income (SSI), the Federal program that provides cash assistance to needy age, blind, and disabled individuals. To qualify for SSI on the basis of disability, an individual must be severely disabled, such that he or she is “...unable to engage in any substantial gainful activity by reason of a medically determined physical or mental impairment expected to result in death or that has lasted, or can be expected to last, for a continuous period of at least 12 months” (U.S. House of Representatives, 2000).

By broadening our knowledge of the disabled population, we can better address the gaps in the current health care system, including identifying areas in which there may be opportunities for more effective and efficient delivery of care for key population subgroups. Further, this information will help States and managed care organizations in developing managed care programs that better meet the varied needs of vulnerable Medicaid beneficiaries.

DATA AND METHODS

Data

We rely on a telephone survey of 816 disabled adult SSI beneficiaries fielded in New York City in 1999-2000. A comparable survey was also fielded in Westchester County, New York. Because the findings were broadly similar in both New York City and Westchester County, for simplicity in presentation we have limited this article to New York City. However, the consistency of the findings for New York City and Westchester County provides some support for the generalizability of these findings beyond New York City.

At the time of the survey, approximately 10 percent of the sample of disabled beneficiaries was already voluntarily enrolled in Medicaid managed care. Most were individuals who had entered Medicaid managed care while enrolled in the Temporary Assistance for Needy Families (TANF) Program and chose to continue in managed care after their eligibility for SSI was established.

The sample for the survey was identified through State enrollment records for the Medicaid Program. Since information on disabling conditions is not available through State program records, we matched with Social Security Administration records for the SSI Program to obtain information on the primary disabling condition. Our study focuses on non-aged adult SSI beneficiaries living in the community. We also limited the study sample to SSI beneficiaries who were to be included in the future switch to mandatory Medicaid managed care. Thus, we excluded from our sample Medicare recipients, individuals receiving long-term care services under Medicaid waiver programs, and the homeless. We also limited the study to those on Medicaid for the entire past year to ensure consistency between the outcome measures describing health care use and the period of Medicaid enrollment. In selecting the survey sample, we stratified on the basis of disabling condition. Random samples were selected within each strata.

1 Voluntary enrollment in Medicaid managed care ranged from 7 percent of those with MR/DD to between 11 and 12 percent of both those with mental illness and those with physical disabilities. Small sample sizes prevent any separate analyses of those individuals.

2 Ninety-seven percent of the sample of SSI beneficiaries was on Medicaid for the full 12 months of the past year.
The survey collected information on access to and use of care, along with socioeconomic, health status, and disability information. Information was sought directly from the Medicaid beneficiary whenever possible. However, there were instances in which the sample member was not able to complete the survey. Approximately 18 percent of the sample members relied on a proxy respondent, including 37 percent of sample members with MR/DD, 15 percent of those with mental illness, and 13 percent of those with physical disabilities. The two most common reasons for using a proxy were language issues and the beneficiary being mentally incapable of responding to the survey. Because of the possibility that responses provided by a proxy differ from those that would have been provided by the sample member if he or she were able to respond to the survey, we control for proxy respondents in the multivariate analysis. However, care must be taken in interpreting that control variable since the presence of a proxy respondent may also capture severity of disability and/or language barriers to care.3

The overall response rate for the survey was 56 percent. Almost all of the non-response was due to an inability to locate sample members rather than a refusal by those who were located to participate in the survey.4 Once a sample member was located, the cooperation rate was 94 percent. Survey weights were developed to reflect the probability of selecting each individual for the survey and to adjust for survey non-response. The adjustments for non-response were based on the administrative data available for both respondents and non-respondents, which included basic demographic information along with primary disabling condition and geographic location. The analyses reported here have been weighted using these sample weights.

Missing data were a relatively minor problem for the explanatory variables included in our regression analysis: less than 3 percent of the individuals had missing values. We used hot-deck imputation procedures to assign values for individuals with missing values for the explanatory variables.

**Measures of Health Care Access and Use**— We focus on key aspects of access to care as presented in a standard analytic framework (Andersen 1968, 1995; Andersen and Aday 1978; Andersen, McCutcheon, and Arday, 1983). We consider potential access and realized access. In this study, potential access is measured as the presence of a usual source of care and unmet need. Realized access is measured by the actual use of health care services, including visits to the emergency room (ER), hospital stays, outpatient visits for physical and mental health care, and receipt of three preventive health care services—a dental care visit, an immunization against influenza, and, for females, a Pap smear. Higher levels of hospital and ER use indicate potential access problems if that use stems from problems obtaining care in other settings. Since we cannot identify avoidable hospitalizations or inappropriate ER use from the survey, we interpret higher levels of hospital and ER use among the disabled Medicaid beneficiaries as suggestive of problems with access to primary care, particularly when combined with high levels of unmet need and difficulties obtaining care.

Finally, we consider the disabled individuals’ assessment of their ease of access to care. Specifically, we asked the survey respondents to rate various aspects of their health care as excellent, very good, good,
fair, or poor. We consider their rating of the ease of finding a doctor who will accept Medicaid and the ease of getting specialist, mental health, and emergency care.

Methods

We conduct both descriptive and multivariate analyses. In the descriptive analyses, we compare individuals with mental illness and MR/DD to those with physical disabilities. This comparison allows us to identify differences in access to and use of health care among the three subgroups.

The multivariate analysis has two objectives: (1) to determine whether the differences in health care experiences among the three subgroups can be explained by differences in their personal characteristics and health care needs, and (2) to identify characteristics of the disabled Medicaid population that are associated with greater difficulties in obtaining care. In addressing these issues, we estimate multivariate models of access and use as a function of the primary disabling condition of the individual—mental illness, MR/DD, or physical disability—and his or her demographic, health, and disability characteristics. The variables included in the multivariate analysis reflect the predisposition of an individual to use services, factors that enable or impede use, and the individual’s need for services (Anderson, 1968). In addition to those measures, we also control for whether the survey responses were obtained from a proxy respondent for the sample member. Since all of the outcome measures are binary variables, we estimate logit regression models.

Results

Overview of the Sample

Health and Disability Status—Although our sample of SSI beneficiaries are all disabled, there is a great deal of variation in their health status and dependency that is reported both within and across the subgroups (Table 1). Among individuals with physical disabilities, two-thirds report that they are in fair or poor health (versus good, very good, or excellent), and almost 75 percent report needing help with activities of daily living (ADLs) i.e., bathing, dressing, eating, transferring, using the toilet, or getting around the home and/or instrumental activities of daily living (IADLs) i.e., meal preparation, shopping, finances, housework, using the telephone, or managing medications. Of particular importance to their ability to access health care, 36 percent reported needing assistance getting around their home (i.e., mobility limitations) and 13 percent reported needing assistance using the telephone.

Compared with the physically disabled, individuals with MR/DD tend to be significantly healthier—almost two-thirds were in good, very good, or excellent health. However, those with MR/DD are significantly more likely than the physically disabled to need help with their daily activities. In general, as might be expected given the nature of their primary disability, individuals with MR/DD require less assistance with ADLs and more assistance with IADLs than the physically disabled. Specifically, we find that MR/DD beneficiaries are less likely to have mobility limitations, but more likely to require assistance.
with meal preparation, shopping, finances, using the telephone, and managing their medications.

In contrast to those with MR/DD, individuals with mental illness report similar levels of health and disability status as those with physical disabilities. Like the physically disabled, about two-thirds of the mentally ill report their health as fair or poor and about 70 percent report needing assistance with one or more ADLs or IADLs. However, the patterns of dependency reported by the two subgroups differ: individuals with mental illness are significantly less likely to need help with bathing, using the toilet, or getting around their home, but more likely to need help managing their medications.

Demographic and Socioeconomic Characteristics—Beyond the health and disability-related challenges to obtaining care, many in the subgroups of SSI beneficiaries face other challenges. For example, many have limited formal education, potential language barriers, and limited financial resources (Table 2). Further, most are from racial and ethnic minorities and, thus, may have difficulties obtaining culturally sensitive care (Mayberry et al., 1999). Among the physically disabled, less than one-half have graduated from high school or speak English as their first language. About 80 percent are Hispanic or black persons and live in families with an annual income of less than $10,000. The situation is similar for those with mental illness,
although they are more likely to be white persons than the physically disabled (33 versus 19 percent).

In contrast, the characteristics of those with MR/DD are significantly different than the physically disabled: individuals with MR/DD tend to be younger and are less likely to have graduated from high school (25 versus 44 percent). However, individuals with MR/DD may tend to face fewer language barriers as they are much more likely to speak English as their first language (69 versus 47 percent) than those with physical disabilities. Individuals with MR/DD also tend to have greater family and financial resources than the physically disabled: They are more likely to live with others, especially parents, and to have higher family incomes. Nonetheless, about 65 percent have family income of less than $10,000 per year.

As might be expected given the differences between the overall population in New York City and the population of the Nation as a whole, the Medicaid population in New York City differs from that in the rest of the Nation.\(^5\) New York City SSI beneficiaries are older (65.9 percent are over age 40, compared with 56.5 percent nationwide), less well educated (40.6 percent have graduated from high school, compared with 56.5 percent nationwide), less likely to be white persons (22.9 percent compared with 33.3 percent nationwide), and less likely to be white persons (22.9 percent compared with 33.3 percent nationwide).

\(^5\)The characteristics of SSI beneficiaries nationwide are unpublished tabulations from the National Survey of America’s Families (NSAF). NSAF is a nationally representative survey of the non-aged adults and children (Kenney, Scheuren, and Wang, 1999).
Further, SSI beneficiaries in New York City are much poorer than SSI beneficiaries nationwide: 77.3 percent report incomes less than $10,000 per year, compared with 41.0 percent for the overall SSI population.

**Access to Care**—Given the challenges faced by the disabled as they seek to obtain care, a key element in their access to care is having a usual source of care (other than the ER). As shown in Table 3, we find evidence that the Medicaid Program in New York City is effective at connecting disabled Medicaid beneficiaries, particularly for those with physical disabilities, to health care providers. Nearly every disabled individual has a usual source of care for physical health. However, somewhat fewer of those with MR/DD and mental illness report a usual source of care for physical health (92 and 89 percent respectively), as compared with those with physical disabilities (97 percent).

As expected, individuals with mental illness are significantly more likely than those with physical disabilities to have a usual source of care for mental health. Nevertheless, about one-quarter of...
individuals who are on SSI because of mental illness do not have a usual source of mental health care.

Beyond having a usual source of care, there is evidence that members of all three subgroups face similar difficulties in accessing care. About 70 percent of all three subgroups report a wait in the office to see their provider of more than 30 minutes, about 40 percent report a travel time to their provider of more than 30 minutes, and about 20 percent report difficulty communicating with their provider because of language problems. While comparable measures for other populations are not available for all the measures included in this survey, the travel and wait times reported here are much higher than national estimates for the general Medicaid and uninsured populations (Cornelius, Beauregard, and Cohen, 1991).

Health Care Use—Consistent with the high share of Medicaid expenditures accounted for by disabled beneficiaries, we find that SSI beneficiaries are frequent users of health care services, including high cost services (i.e., inpatient and ER care). Almost one-third of the physically disabled and one-quarter of the mentally ill reported a hospital stay in the past year, with many reporting more than one stay. Similarly, more than one-half of those with physical disabilities and nearly one-half of those with mental illness reported an ER visit. Moreover, more than one-half of those individuals reported multiple ER visits over the past year. As expected, given their better health status, hospital stays and ER visits were less common for individuals with MR/DD; however, they were still substantial users—15 percent reported a hospital stay and 39 percent an ER visit in the last year. (To place these figures in context, among adults nationally, 7 percent report a hospital stay and 21 percent an ER visit over a year) (Coughlin, Long, and Kendall, forthcoming).

Not surprisingly, individuals with mental illness were significantly more likely than the physically disabled to have hospital stays and ER visits related to their mental health. Hospital stays associated with mental health were also more common for those with MR/DD.

As one would hope for a disabled population, nearly everyone (90 to 96 percent) in all three subgroups of SSI beneficiaries reported some type of outpatient visit for physical or mental health in the past year. However, although the differences are not great, significantly fewer of those with mental illness and MR/DD reported an outpatient visit for physical health care than did the physically disabled (89 and 87 percent, respectively, versus 95 percent). Thus, about 1 in 10 of both those with mental illness and those with MR/DD did not have a visit for their physical health in the past year.

Of greater concern, only 75 percent of those on SSI because of mental illness had an outpatient visit for mental health care over the past year. No doubt this reflects the finding reported earlier that only 75 percent of those with mental illness have a usual source of care for mental health.

As a doctor visit is often required to receive preventative care, the lack of outpatient visits for physical health for about 10 percent of those with mental illness and MR/DD raise concerns about access to preventative care for those individuals. Direct measures of access to specific types of preventative care for those who had a health care visit adds to those concerns about access to preventative care. We find evidence that sizable minorities of SSI beneficiaries across the three subgroups are not receiving basic preventative care—an annual dental visit, a flu shot (recommended for the aged and disabled) and, for females, a Pap smear. About one-third of the physically disabled did not receive dental
care over the past year, about 60 percent did not receive a flu shot, and, among females, almost 25 percent did not receive a Pap smear. Similar levels are reported for the mentally ill, while those with MR/DD do better on some measures and worse on others. The MR/DD subgroup is significantly more likely than the physically disabled to have had a dental visit, but less likely to have had a flu shot and, among females, less likely to have received a Pap smear.

**Unmet Need**—Despite having a usual source of care and using high levels of health care services, many SSI beneficiaries reported that they did not get care that they felt they needed. Unmet need is of particular concern for this population as it may indicate a health problem that is not being addressed, which may result in poor health outcomes for the individual and high costs to the health care system.

About one-third of the physically disabled report not getting care that was needed for one or more types of care. The pattern of unmet need reported by those with MR/DD was similar to that of the physically disabled. In contrast, significantly higher levels of unmet need were reported by those with mental illness. Nearly one-half of the beneficiaries with mental illness reported unmet need for one or more types of care, including 18 percent reporting unmet need for doctor care, 17 percent reporting unmet need for prescription drugs, and 11 percent reporting unmet need for mental health care. In short, individuals with mental illness appear to have greater difficulty navigating both the physical and mental health care delivery systems.

**Ease of Obtaining Care**—Finally, substantial shares of SSI beneficiaries across the three subgroups rated their ability to access care as fair or poor. About 30 percent of all three groups rate the ease of finding a doctor who accepts Medicaid as fair or poor. Between 20 and 40 percent report the ease of getting specialist medical care, mental health care, or emergency care as fair or poor.

**Multivariate Analysis**

The differences in access and use among individuals with physical disabilities, mental illness, and MR/DD may reflect systematic differences in access to care for individuals with different disabling conditions. Alternatively, the differences may reflect differing health care needs of the individuals within the subgroups. Using a regression framework, Table 4 explores the extent to which the differences in health care experiences by those with physical disabilities, mental illness, and MR/DD reflect personal characteristics and health care needs, as measured by demographic characteristics, health status, and ADL and IADL dependencies. As in the descriptive analysis, we compare individuals with mental illness and MR/DD to those with physical disabilities. For ease of comparison across outcomes, we report the results from the logit models as odds ratios. The $F$-test provides an assessment of the overall explanatory power of the models.

As shown in Table 4, a number of the differences in access and use found in the descriptive analysis are no longer significant after controlling for demographic characteristics and health care needs. Most notably, individuals with MR/DD are no longer significantly less likely to have a usual source of care for physical health nor an outpatient visit for physical health than the physically disabled. Likewise those with mental illness are no longer less likely to have an outpatient visit for physical health.
Table 4
Odds Ratios from Logit Regression for Selected Access and Use Measures for Adult SSI Recipients: New York City, 1999-2000

| Explanatory Variable | Has Usual Source of Care for Physical Health | Has Usual Source of Care of Mental Health | Had Hospital Stay | Had Multiple Hospital Stays | Had ER Visit | Had Multiple ER Visits | Had Outpatient Visit for Physical Health | Had Outpatient Visit for Mental Health |
|----------------------|---------------------------------------------|------------------------------------------|------------------|-----------------------------|-------------|-----------------------|------------------------------------------|--------------------------------------|
| Sample Size          | 811                                         | 808                                      | 812              | 809                         | 801         | 795                   | 813                                      | 810                                  |
| Mental Illness       | *0.314                                      | *11.976                                  | 0.743            | 1.073                       | 0.817       | 1.155                 | 0.926                                    | *9.002                               |
| MR/DD                | 0.653                                       | *3.065                                   | *0.293           | 0.493                       | *0.504      | 0.807                 | 0.482                                    | *2.073                               |
| Age (Years)          | *1.047                                      | 1.013                                    | **0.980          | 0.987                       | **0.985     | **0.981               | 1.029                                    | 1.005                                |
| Female               | 1.792                                       | 1.241                                    | 1.213            | 1.244                       | **1.454     | 1.169                 | 2.89                                     | 1.323                                |
| Black, Non-Hispanic  | 1.694                                       | 0.847                                    | 0.963            | 0.713                       | 1.367       | 1.356                 | 1.395                                    | 0.635                                |
| Hispanic             | **2.140                                     | 1.488                                    | 1.177            | 0.941                       | 1.024       | 1.326                 | **2.389                                  | 1.327                                |
| Fair or Poor Health  | 1.201                                       | 0.901                                    | *2.012           | 1.493                       | 1.351       | 2.260                 | 1.110                                    | 0.974                                |
| Mobility Limitation  | 0.844                                       | 0.980                                    | 1.378            | *3.094                      | 1.264       | **1.826               | 2.011                                    | 0.923                                |
| Number of Other ADLs | 1.150                                       | 1.178                                    | 1.131            | 0.880                       | 1.120       | 1.005                 | 1.069                                    | 1.028                                |
| Number of IADLs      | 1.002                                       | 0.991                                    | 1.099            | 1.091                       | 1.075       | 0.977                 | 1.190                                    | 1.101                                |
| Survey Respondent is Proxy | 2.677                                  | **1.725                                  | 0.945            | 1.327                       | 0.739       | 1.009                 | **4.128                                  | 1.351                                |
| F-test               | *3.20                                       | *11.94                                   | *4.83            | *2.93                       | *3.19       | *2.93                 | *4.37                                    | *10.61                               |

See notes at end of table.
### Table 4—Continued

Odds Ratios from Logit Regression for Selected Access and Use Measures for Adult SSI Recipients: New York City, 1999-2000

| Explanatory Variable | Had Dental Visit | Had Flu Shot | Had Pap Smear (Female) | Had Any Unmet Need | Had Unmet Need for Doctor Care | Had Unmet Need for Mental Health Care | Rates Ease of Finding Doctor for Medicaid as ER Care as Fair or Poor | Rates Ease of Getting Specialist, Mental Health, or ER Care as Fair or Poor |
|----------------------|-----------------|--------------|-----------------------|-------------------|-------------------------------|--------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|
| Sample Size          | 760             | 784          | 453                   | 816               | 804                           | 809                                  | 776                                                           | 816                                                           |
| Mental Illness       | 1.13            | 0.948        | 0.923                 | *1.824            | **1.729                       | **2.790                              | 0.771                                                         | 0.995                                                         |
| MR/DD                | 1.27            | 0.780        | 0.728                 | 0.763             | 0.824                         | 0.912                                | 0.686                                                         | 0.669                                                         |
| Age (Years)          | 0.990           | 1.008        | 1.002                 | 0.987             | 0.999                         | *0.941                               | **0.979                                                       | *0.976                                                       |
| Female               | 0.965           | 1.112        | —                     | 1.216             | 1.116                         | 1.531                                | *0.652                                                        | **1.465                                                       |
| Black, Non-Hispanic  | 0.799           | *2.151       | 1.445                 | 0.964             | 0.811                         | 0.893                                | *0.502                                                        | 0.976                                                         |
| Hispanic             | 0.9556          | *2.016       | **1.832               | 0.858             | 0.869                         | 0.881                                | *0.453                                                        | 0.687                                                         |
| Fair or Poor Health  | 1.264           | 1.259        | 1.522                 | 1.346             | 1.492                         | **2.875                              | 1.388                                                         | **1.556                                                       |
| Mobility Limitation  | 0.831           | 1.360        | 0.941                 | **1.730            | 0.691                         | 1.067                                | 0.616                                                         | 1.587                                                         |
| Number of Other ADLs | 0.925           | 1.036        | 1.099                 | 0.895             | 0.991                         | 0.933                                | 1.148                                                         | 0.963                                                         |
| Number of IADLs      | 1.029           | 0.987        | *0.856                | 1.027             | 1.033                         | 1.015                                | 1.001                                                         | 1.061                                                         |
| Survey Respondent is Proxy | *1.770   | 1.472        | 0.693                 | 0.636             | **0.445                       | 0.561                                | 0.660                                                         | 0.898                                                         |
| F-test               | 1.48            | *2.29        | **2.19                | *3.09             | **1.89                        | *2.71                                | **2.18                                                        | *2.75                                                         |

* Significantly different from zero at the 0.01 level.
** Significantly different from zero at the 0.05 level.

NOTES: SSI is Supplementary Security Income. ER is emergency room. MR/DD is mental retardation/developmental disabilities. ADLs are activities of daily living. IADLs are instrumental activities of daily living.

SOURCE: New York Survey of Working-Age Disabled Medicaid Recipients, 1999-2000.
Nevertheless, some differences do persist after controlling for health needs. This suggests that the underlying cause of the individual’s disability plays a role in his or her access to care under Medicaid. For example, after controlling for health needs, individuals with mental illness continue to be less likely than the physically disabled to have a usual source of care for physical health and more likely to report unmet need overall and unmet need for doctor care and mental health care. Similarly, individuals with MR/DD remain less likely than those with physical disabilities to have either hospital stays or ER visits. Both those with mental illness and those with MR/DD also continue to be more likely than the physically disabled to have a usual source of care for mental health and to have an outpatient visit for mental health. (However, this may reflect our inability to control for mental health needs in the full sample; our measures of health and disability status do not include an assessment of mental health.) Overall, these findings suggest greater difficulty in obtaining care for those with mental illness and somewhat better access to care for those with MR/DD, as compared with physically disabled individuals with similar health status and disability levels.

Beyond their disabling condition, other aspects of the individual’s health and disability status (e.g., health status, functional limitations) have only limited effect on the ability to obtain care. However, there are some areas of concern. Most notably, individuals with mobility impairments and those in fair or poor health appear to face greater barriers to care. Perhaps in conjunction with that, we also find that these individuals are more likely to use high cost inpatient and ER care. Specifically, those with mobility limitations are significantly more likely than those without such limitations to report unmet need and to rate the ease of getting care as fair or poor. They are also more likely to have multiple hospital stays and ER visits. Similarly, individuals in fair or poor health are more likely than those in better health to rate the ease of getting care as fair or poor and to report unmet need. They also are more likely to have hospital stays and multiple ER visits.

While the higher levels of use by both those with mobility impairments and those in fair or poor health may reflect their greater health care needs, their assessment of the ease of obtaining care and their use of multiple ER visits raises the possibility that some of the high cost service use could be avoided by improving access to primary and preventative care: Individuals in fair or poor health and those with mobility limitations are no more likely to have a usual source of care for physical health, outpatient visits for physical health, or to receive preventative care than are those who report better health and less disability.

DISCUSSION

This article uses newly available survey data to provide an in-depth look at disabled adult Medicaid beneficiaries with physical disabilities, mental illness, and MR/DD. To our knowledge this is the first such detailed examination of the health care needs and experiences of these vulnerable Medicaid beneficiaries. Although the study is limited to a single city in a single State and thus, may not be generalized to other areas, it provides a more extensive look at this population of vulnerable Medicaid beneficiaries than has been possible with existing data sources. Further, because New York has a longstanding tradition of funding one of the Nation’s most comprehensive Medicaid Programs, our study provides insights into the circumstances of individuals on Medicaid in a State with a comparatively well-funded
Medicaid Program. While the findings for New York City and Westchester County are suggestive of problems under the Medicaid Program for disabled beneficiaries beyond New York, studies in other locations are needed to assess the extent to which the challenges faced by disabled Medicaid beneficiaries in New York City differ from those faced by disabled beneficiaries in other settings and under other, less comprehensive Medicaid Programs.

As would be expected given the variation in the disabling conditions among disabled Medicaid beneficiaries, we do find differences in health care needs across the three subgroups. For example, two-thirds of those with physical disabilities and mental illness rate their health as fair or poor, and 70 percent report needing assistance with daily activities. However, individuals with physical disabilities are more likely to need help with ADLs (especially help with bathing, toileting, and getting around their home), while those with mental illness are more likely require assistance with IADLs (especially help with medications). Individuals with MR/DD tend to be healthier than members of the other two subgroups—only about one-third are in fair or poor health; however, 85 percent need help with one or more activities of daily life (especially IADLs).

Despite the differences in their health care needs, we find many similarities in health care use across the three subgroups, including frequent use of high-cost care, limited use of preventative care, and high levels of unmet need. For example, about one-half of those with physical disabilities and mental illness had an ER visit in the past year, as did almost 40 percent of those with MR/DD. Further, about one-quarter of the members of all three subgroups had multiple ER visits. Unmet need was reported by nearly one-half of those with mental illness, one-third of the physically disabled, and one-quarter of those with MR/DD.

Although there are many similarities in their health care experiences under Medicaid, there is also evidence that some disabled individuals experience greater barriers in their efforts to obtain care. In particular, the underlying cause of an individual’s disability appears to play a key role in his or her access to care under Medicaid, with individuals with mental illness facing greater difficulties obtaining care than the physically disabled after controlling for health care needs. Of special concern, one-quarter of individuals with mental illness did not have usual source of care for mental illness and only 75 percent had an outpatient visit for mental health over the past year.

Traditionally, the mental health care system under Medicaid in New York, as in most States, has relied heavily on inpatient and institutional care. While the State is now investing in more community-based mental health care, the lack of available services and the fragmented and episodic nature of the system of community-based providers has made getting such care difficult (New York State Office of Mental Health, 2001). As a result, it is likely that the access problems faced by those with mental illness in New York City reflect the complexity of securing mental health care under the Medicaid Program in the city. Overlaying these structural barriers, persons with mental illness, because of their health condition, may also have greater difficulty navigating any health care system.

Beyond disabling condition, we also find that individuals with mobility limitations and those in fair or poor health face greater barriers to care. Perhaps because of that, they are more likely to use high cost hospital and ER care than individuals without those limitations.
The challenges faced by disabled individuals in New York City as they seek care under the existing Medicaid Program reflect both systemwide problems and difficulties associated with specific health or disability limitations (such as mental illness, poor health, and mobility limitations). Problems with the health care system that affect all disabled beneficiaries include too few doctors willing to accept Medicaid patients and a lack of emphasis on preventative care. To address these access issues, there is a need for changes in the health care system that is in place under Medicaid (e.g., inducing more doctors to serve Medicaid patients, increasing the emphasis on preventative care) as well as improvements in the assistance provided to specific disabled individuals. The latter would include providing transportation services to physician visits for those with mobility limitations and providing case managers for individuals in fair or poor health and individuals with mental illness to help them navigate the system and to ensure they receive the care that is needed. New York policymakers have acknowledged the special challenges faced by persons with mental illness and have made case management support for individuals with mental illness a key component of its mental health system (New York State Office of Mental Health, 2001).

As policymakers in New York and other States introduce managed care to disabled Medicaid beneficiaries, it is important that they bear in mind the diversity of needs and circumstances of Medicaid beneficiaries who have disabilities as well as the range of access problems they currently face under the Medicaid Program. A managed care program that provides a strong home for medical and mental health care, care coordination, transportation services, and a focus on preventive care could go a long way toward addressing the gaps in coverage that exist under the Medicaid Program for disabled beneficiaries in New York City. Whether it is possible to improve access to care for disabled Medicaid beneficiaries while reducing Medicaid costs will depend on whether the costs of providing the increased services and addressing the unmet need that exists among the disabled population is offset by savings generated from reducing avoidable ER visits and hospital stays.

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