

**Awareness and Access to Care
for Children and Youth with Epilepsy**

Needs Assessment: Final Report

Submitted to
the District of Columbia
Maternal and Family Health Administration

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Executive Summary

In fall 2004, the Department of Health of the District of Columbia undertook a demonstration project, “Awareness and Access to Care for Children and Youth with Epilepsy,” with the goal of developing, implementing, and evaluating systems strategies to improve access to information and care for children and youth with epilepsy in underserved areas of the District. The project included as one component a needs assessment, the first ever conducted in the District, to gather information regarding children with epilepsy, with a particular focus on children living in designated Medically Underserved Areas (MUAs). The needs assessment is intended to highlight needed changes within the health services delivery system for children and youth with epilepsy and provide relevant information for strategic planning and development of subsequent activities. It is based on a review of the literature, existing data from Medicaid managed care organizations (MCOs) and on clients in fee-for-service Medicaid, hospital discharge data, a report on interviews with key informants, a report on a survey of school nurses, and findings from focus groups with young adults with epilepsy and caretakers of young adults with epilepsy.

Based on our analysis of Medicaid data (MCO and fee-for-service), we estimate that there are 850 children ages 0 to 21 with epilepsy covered by Medicaid in the District. Prevalence is fairly evenly distributed across age groups. Somewhat less than half (43.8 percent) of Medicaid-enrolled children with epilepsy reside in designated MUAs. The highest geographic concentration of Medicaid-covered children with epilepsy is found in the southeast quadrant of the city.

Key informants, school nurses, and children with epilepsy and their caretakers expressed differing views of the adequacy of the service delivery system. Clients in the system clearly felt that the care they received was good, but also clearly did not have sufficient information for a completely informed judgment. Armed with greater knowledge, providers in the system were better able to see the gaps in care.

In general, children and their caretakers were quite pleased with the care they receive. Enrollees in Health Services for Children with Special Needs were particularly appreciative of the coordination of care that this MCO provides. Staff at Children’s National Medical Center and a particular neurologist at Howard University Hospital received high praise. However, focus group participants identified emergency room staff and school nurses as needing a better understanding of epilepsy and how to treat and support children with epilepsy. The findings of the school nurse survey support the need for additional information and/or training for this group.

Key informants viewed the system less favorably, citing several gaps in and barriers to care including the limited availability of pediatric neurologists, restricted MCO formularies for anticonvulsant medications, and cumbersome MCO referral requirements. They were markedly less positive about the care coordination provided by MCOs. The lack of a designated contact at the Department of Health and insufficient coordination and communication across different parts of the system were cited as contributing to inefficiencies. In addition, informants cited lack of knowledge about epilepsy on the part of families and emergency room providers, in particular, as impediments to successful treatment, views corroborated by the focus group findings.

The analysis of hospital data revealed differences in admissions for epilepsy and convulsions between Medicaid clients ages 0 to 21 and clients with other insurance coverage. Admissions for epilepsy and convulsions, an ambulatory care sensitive condition, were about 50 percent higher for Medicaid clients as compared to only 35 percent higher for the reference condition of febrile convulsions, a nonambulatory care sensitive condition. These results suggest possible insufficiencies in ambulatory care services for Medicaid epilepsy clients. The insufficiencies might reflect difficulties in primary care access by Medicaid enrollees, inadequate experience with epilepsy among primary care providers, inadequate access to epilepsy specialists, or poor patient compliance with recommended treatments. Other possible explanations include a greater acuity of disease and more comorbidities among low-income persons and longstanding patterns of emergency room use by Medicaid enrollees.

The final section of the report provides detailed recommendations on improvements that might contribute to a more effective system in the District based on the findings of the needs assessment. The recommendations are specific to the goals identified by the Department of Health under this project:

- Achieve early detection, diagnosis, and treatment of epilepsy
- Improve access to a medical home
- Address the stigma associated with epilepsy
- Identify and address the language and cultural barriers in MUAs
- Develop and implement strategies for sustaining systems change

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INTRODUCTION

Epilepsy is a chronic neurological condition affecting an estimated 2.5 million people in the United States.¹ The very young and the elderly are most likely to be affected.² Among inner city populations, the clinical management of epilepsy can be a serious problem because of limited finances, low education levels, lack of insurance, limited accessibility of services, lack of good knowledge about the condition, and, for children, problems with caretakers.³

In fall 2004, the Department of Health of the District of Columbia (DC-DOH) undertook a demonstration project, “Awareness and Access to Care for Children and Youth with Epilepsy,” with the goal of developing, implementing, and evaluating systems strategies to improve access to information and care for children and youth with epilepsy in underserved areas of the District. The project included as one component a needs assessment, the first ever conducted in the District, to gather information regarding children with epilepsy, with a particular focus on children living in designated Medically Underserved Areas (MUAs). The District has 188 census tracts, of which 65 (35 percent) currently have MUA status.⁴

The needs assessment is intended to highlight needed changes within the health services delivery system for children and youth with epilepsy and provide relevant information for strategic planning and development of subsequent activities. It draws on several sources of information. We began with a review of the literature on epilepsy treatment and on services for children with special health care needs, including epilepsy.⁵ Three sources of quantitative data were made available to us. We used existing data submitted by the four Medicaid managed care organizations (MCOs) participating in the project and data on fee-for-service Medicaid clients to estimate the number of children covered by Medicaid in the District who have epilepsy and the share of those children who live in designated MUAs.⁶ In addition, we used hospital discharge data supplied by the DC-DOH to estimate rates of admission to District hospitals for epilepsy or seizures and compare the rate of admissions for Medicaid and non-Medicaid children.⁷ Qualitative sources included a report on interviews with key informants conducted by Hess Health Policy, a report on a survey of school nurses conducted by the Department of Health, and findings from focus groups conducted by LaScola Qualitative Research.⁸

In this report, we first discuss the findings from the literature. We then present estimates of the number of Medicaid children and youth with epilepsy in the District from our analysis of the MCO data. Next, we use the key informants interview report, the report of the school nurses survey, and the focus group findings to assess the services available to children and youth with epilepsy in the District from the point of view of both providers and children and families who use the services. In this section, we pay special attention to services available to help young adults make the transition from pediatric services to adult services, an area of particular interest to DC-DOH. We then present a comparison of hospitalization rates for children with epilepsy across insurance types as one measure of the effectiveness of services for this population. In the final

section, we discuss the characteristics of an effective system of care for children and youth with epilepsy and provide recommendations to the DC-DOH on improvements that might contribute to a more effective system in the District.

REVIEW OF THE LITERATURE

Methods

We conducted an extensive search for literature relevant to health services for children with epilepsy in the District of Columbia's MUAs, using PubMed, Lexis Nexis, Google, Google Scholar, and the Urban Institute's journal database. We found little research specific to the District of Columbia and MUAs and so broadened the search to include more general, yet relevant, topics. Key words used as search criteria in various combinations included epilepsy, children, pediatric, underserved, low-income, poor, utilization, and specialty care. An effort was also made to find literature that presented the most current standards of care in pediatric epilepsy to present a baseline for comparison of health services received by children in MUAs. Most of the literature searches covered the years 2000 to 2006. The articles were drawn primarily from medical and health policy journals but also from materials aimed at people with epilepsy, such as web sites for large epilepsy education and advocacy groups.⁹

Findings

With only a few exceptions, the literature on epilepsy in children and youth is of a general nature; that is, it does not relate to specific geographic areas such as the District of Columbia. Nonetheless, there is much to be learned from this literature that could be applied to the treatment of children and youth with epilepsy in the District. In this section, we identify findings from the literature that pertain to recommendations in this report.

The majority of epilepsy cases have no identifiable cause.¹⁰ The literature is consistent in recommending early identification and treatment of cases.¹¹ However, diagnosis can be difficult, and so at least one study argues against treatment with anti-epileptic drugs (AEDs) after a first unprovoked seizure in childhood unless further evidence supports a diagnosis of epilepsy because of the side effects of these medications.¹²

The literature suggests that only 50 to 70 percent of all cases are well controlled.¹³ One study estimates that up to 85 percent of cases have the potential for full or partial control of seizures.¹⁴ The process for finding effective treatment requires careful selection of medications from among both older and newer therapies as well as identification of alternative treatments, such as surgery, vagus nerve stimulation, or dietary interventions, for cases not responsive to AEDs.¹⁵ There is evidence that the efficacy of treatment varies according to the particular epilepsy syndrome, so accurate diagnosis is important for successful treatment.¹⁶

Control of seizures is important in young children to minimize the developmental and behavioral problems associated with uncontrolled seizures.¹⁷ For school-age children, the effect on school attendance and performance must also be considered since even mild forms of epilepsy are frequently associated with attention, behavioral, and learning problems.¹⁸ For children and young adults, poor control of seizures is associated with low

self esteem and other psychosocial problems, including a high prevalence of depression.¹⁹ Early identification and treatment allows the development of family and other support systems at critical periods in the child's development and interventions to address the related social and psychological effects.²⁰ In addition to interventions to control seizures, the literature recognizes the importance of addressing the mental health needs of children and youth with epilepsy and providing information and support for their caretakers.²¹

Not surprisingly, health care utilization by children and youth with epilepsy is generally higher than that of other children.²² Insurance coverage—Medicaid/SCHIP and employer-sponsored insurance—and plan type—fee-for-service (FFS) and managed care organization (MCO)—are associated with different patterns of care,²³ as is socioeconomic status.²⁴ In particular, studies show that hospitalization rates for epilepsy are higher among lower socioeconomic groups in Canada,²⁵ and reductions in hospitalizations were observed for ambulatory care sensitive conditions, including epilepsy, with increased enrollment in the California SCHIP program.²⁶ Race was also reported to be associated with higher emergency department use in Michigan among children with special health care needs, with African Americans more likely to visit the emergency department than other racial groups.²⁷

Case management is reported to be an important factor in improving access to care for children with special health care needs. In a study that included consideration of the District's program, Health Services for Children with Special Needs (HSCSN), case management was identified as one of the most important factors explaining improved access for HSCSN enrollees over fee-for-service enrollees. Higher physician reimbursement was also seen as a likely contributing factor.²⁸ In another study of five state programs, including the District's, states with a managed care plan dedicated to children with special needs were judged as the most successful overall.²⁹

Much of the research on utilization of services looks broadly at all children with special health care needs. All of the studies cited here either are focused on epilepsy or include it as one of the defining conditions. Epilepsy is less common than many other chronic pediatric conditions, and at least one study specifically notes that utilization patterns by children with epilepsy differ from those of children with other conditions.³⁰ Thus, conclusions drawn from broad studies of children with many and often multiple conditions should be applied cautiously to programs for children with epilepsy to test their validity.

PROFILE OF THE MEDICAID POPULATION OF CHILDREN AND YOUTH WITH EPILEPSY

Data

An important input to the epilepsy needs assessment is a determination of the size and geographic distribution of the population with this diagnosis. We attempted to estimate the number of persons ages 0 to 21 years with epilepsy who live in MUAs. Only Medicaid data (both MCO and FFS) were available for this purpose. Because MUAs are designated in part by poverty level, a focus on Medicaid enrollees, whose eligibility is determined primarily by their low income, is consistent with the project goals. In addition to obtaining a count of the Medicaid pediatric population with epilepsy, we were able to

map most of these individuals to MUAs and non-MUAs to show their geographic distribution across the District.

The four MCOs that participate in the DC Medicaid program (Amerigroup, DC Chartered Health Plan, Health Right, and Health Services for Children with Special Needs) were asked to provide data on enrollees ages 0 to 21 years with a diagnosis of epilepsy. The MCOs established their own criteria for a qualifying epilepsy diagnosis. The DC Medical Assistance Administration provided comparable data for children in the FFS system. Because only some MCOs provided multiyear data, only enrollees in 2005 were used in the analysis. Further, only patients with DC addresses were included.³¹

Findings

Number of Medicaid pediatric epilepsy cases: We combined the MCO and FFS system datasets and eliminated 17 apparent duplications between the two files.³² The combined MCO/FFS population, with duplicates removed, totaled 850. This number represents our best estimate from these data of the population of children and youth with epilepsy enrolled in Medicaid in the District.

In order to estimate the prevalence of epilepsy, we used data from the Medicaid Statistical Information System (MSIS) to estimate the population of children ages 0 to 21 on Medicaid in the District.³³ MSIS data were not yet available for 2005 at the time of this analysis so we use data from 2004 when average monthly enrollment was 76,176. The combined MCO-FFS population of 850 implies an epilepsy prevalence rate of 11 per thousand District children on Medicaid. This rate is slightly higher than seen in the nation as a whole. Estimates of the national prevalence for all age groups range from 4 to 10 per thousand.³⁴ One study estimated the prevalence of epilepsy in children (ages 0 to 19) in Oklahoma at 4.7 per thousand, noting that the prevalence was 1.8 times higher among African Americans.³⁵ The higher observed prevalence among African Americans, the District's majority population, might partially explain the higher prevalence we found in the Medicaid data.

As noted above, the data from which this prevalence number was compiled were submitted by participating MCOs using their own definition of an enrollee with epilepsy. Diagnosis codes (ICD-9s) were included in some files, but not in all, so that we were unable to standardize the definition of a case of pediatric epilepsy. Thus, it seems likely that the MCOs, in seeking completeness in the data file, might have included cases that would not meet a standard definition. This lack of consistency across the files likely contributes to what appears to be a higher than expected prevalence rate.

The MCO and FFS program data varied to such an extent that there was no consistency on any fields (e.g., race, gender) to generate descriptive statistics for the entire Medicaid population with epilepsy. The one exception is date of birth. An age distribution is presented in table 1 (next page). Prevalence is fairly evenly distributed across five-year age groups, with slightly higher prevalence among young adolescents and slightly lower among older adolescents.

Geographic distribution of Medicaid pediatric epilepsy cases: Complete addresses were available for most enrollees to allow for mapping. We eliminated 56 enrollees from mapping because their address of record was a social services agency

address, two with post office boxes addresses only, and one with an address unrecognized by the US Postal Service zip code finder. Another 19 were unable to be geocoded during

Table 1

Age Distribution of DC Medicaid Enrollees with Epilepsy Diagnosis (calendar year 2005)

Age	Count	Percent	Cumulative Percent
Less than 1 year	24	2.8	2.8
1 year	43	5.1	7.9
2–5 years	167	19.6	24.7
6–10 years	198	23.3	42.9
11–15 years	241	28.4	51.6
16–21 years	177	20.8	49.2
Total (0–21 years)	850	100.0	100.0

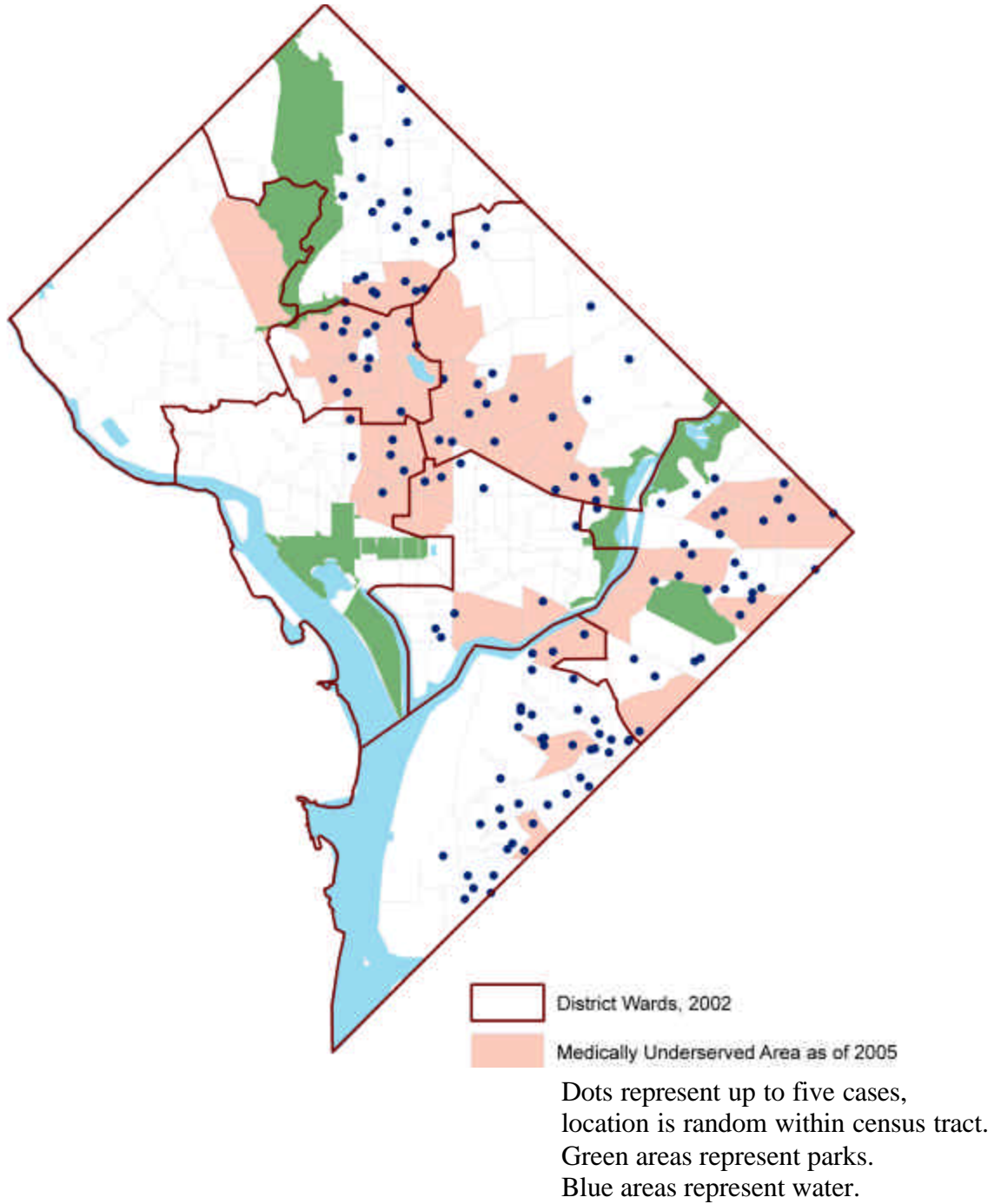
Source: DC Medical Assistance Administration, Amerigroup, Chartered Health Plan, Health Right, and Health Services for Children with Special Needs.

the mapping process, suggesting errors in the address. Thus, our map represents 772 children, or about 91 percent of all enrollees in our dataset. The map (figure 1, next page) was created using the software ArcGIS. As part of the mapping process, each child was assigned a census tract identification number based on his or her address. The tract-level data are displayed on a map showing census tracts, ward boundaries, and MUAs.³⁶

MUAs are designated at the census tract level by the federal government according to the Index of Medical Underservice. The index takes into account the concentration of primary care physicians, infant mortality rate, percentage of the population below the poverty level, and percentage of the population over age 65. The score achieved on the index determines whether a given census tract would qualify for MUA designation. However, not all qualifying tracts are so designated since designation requires application, a process that is initiated at the state or local level. Thus, it is important to keep in mind in considering the map that some tracts that meet the criteria for a medically underserved area may not be formally designated as such.

Mapping showed that of the 772 children and youth with epilepsy covered under Medicaid for whom useable addresses were available, 338 (43.8 percent) live in designated MUAs and 434 (56.2 percent) live in non-MUA designated census tracts. The highest concentration of enrollees with epilepsy is found in the southeast quadrant of the city. Cases are scattered throughout the north central part of the city as well. In the far northwest, where there are two MUA-designated census tracts, there are no Medicaid pediatric epilepsy cases.

Figure 1: Distribution of Medicaid pediatric epilepsy cases and designated medically underserved areas (MUAs)



PERSPECTIVES ON THE SERVICE DELIVERY SYSTEM

In this section, we present findings from three different perspectives on the service delivery system for children and youth with epilepsy—the key informants report, the focus group report, and the school nurses survey report. The key informants report is based on interviews conducted in August 2005 with 10 people knowledgeable about services for children with epilepsy in the District using a standardized interview protocol. The informants included health care providers (both specialists and primary care providers), parent representatives, and service providers. Findings in the key informants report are presented in four areas—barriers to care, quality of care, working with DC government agencies, and transition services. We follow this format in this section, adding information from the focus groups, the survey of school nurses, and the data analysis to each area, as appropriate.

The focus group report was based on two focus groups, one with young adults with epilepsy and the other with caretakers of young adults with epilepsy, held in June 2006 using standard moderator guides. The specific topic of investigation was services available to young adults with epilepsy as they aged into adult services, although much was also learned about current use of services. The survey of school nurses was completed in April-May 2005 and covered the nurses' experience with children with epilepsy and any perceived need for further education on epilepsy to help them manage these children's care.

It should be kept in mind that the findings presented in this section are based on qualitative research using responses from selected informants and from caretakers and young adults in small focus groups. Some identified key informants chose not to be interviewed for the study, some caretakers and young adults chose not to join the focus groups, some school nurses did not respond to the survey.³⁷ Therefore, the views expressed here represent the opinions of a small group of people, albeit a very knowledgeable group, whose opinions reflect their own experiences in the system. Other people might have had quite different experiences.

Despite this caveat, there is sufficient consistency on several points to lend overall credibility to the findings. The differences between key informant opinions and those of caretakers and young adults, while instructive, should not necessarily be taken as conflicting information. Clients in the system clearly felt that the care they received was good, but also clearly did not have sufficient information for a completely informed judgment. Armed with greater knowledge, providers in the system are better able to see the gaps in care.

Barriers to care

The District has the highest ratio of total neurologists per 100,000 population in the country, 11.0, as compared with, for example, 7.3 for Massachusetts and 6.8 for Maryland.³⁸ There is no comparable statistic available for pediatric neurologists. One expert suggests that, as a rule of thumb, there should be one pediatric neurologist for every 100,000 population.³⁹ By this metric, the District has an ample supply of pediatric

neurologists. Children's National Medical Center (CNMC) has 22 practicing pediatric neurologists,⁴⁰ and there are also pediatric neurologists at Howard University Hospital and Georgetown University Hospital.⁴¹ Even assuming no other practicing pediatric neurologists in the District, the 22 CNMC practitioners represent well over the one per 100,000 standard. However, CNMC serves not just the District but the greater Washington area, which has a population of about 3.7 million (inner core and inner suburbs),⁴² and there are likely to be pediatric neurologists practicing outside of the District. It is also not known how many pediatric neurologists accept Medicaid clients. Thus, determining whether the supply of pediatric neurologists in the metropolitan area is adequate is not straightforward.

Despite the relatively high supply of pediatric neurologists, key informants reported that it can be difficult for children to get a timely appointment with a neurologist, particularly for an initial diagnosis. They also noted that pediatric neurologists continue to follow patients as they become adults due to a lack of adult neurologists with a specialty in epilepsy. It is not clear whether the difficulty in getting timely appointments is due to inadequate supply or to other factors. For example, MCO practices, such as cumbersome referral requirements and the need for prior authorizations for service, were cited by key informants as barriers to care. Reimbursement rates that are the same for children with special health care needs as for those without were seen as a further disincentive to serve this population. Finally, key informants reported that children with other neurological problems effectively compete with children with epilepsy for scarce pediatric neurology appointments.⁴³

Service providers identified other barriers to care.⁴⁴ In particular, they were concerned about the limited number of anticonvulsant drugs on MCO formularies. Transportation was also seen as a problem.

In contrast, most focus group participants seemed generally pleased with their access to doctors and the attention that they received from their neurologists. Many had been with the same neurologist for a long time and had developed close ties with them and their office staffs. Focus group participants included enrollees from three of the four participating MCOs, and the level of satisfaction varied across the plans. Overall comments strongly suggested that the participants highly valued the care coordination provided by HSCSN, and that such coordination and the access it provided were important anchors in what can be an unpredictable illness.⁴⁵

Participants noted that it could sometimes take a long time to get an appointment for needed services, such as physical therapy, and that sometimes transportation services were not prompt. Transportation, however, was not seen as a large problem, nor was the limited range of the medications that was cited by key informants. When pressed for gaps in their care, participants noted that emergency room staff and school nurses were not always adequately familiar with epilepsy.⁴⁶

The survey responses of school nurses support the focus group participants' assertion that they could profit from additional training in working with children with epilepsy. Less than half said they were "overall very comfortable" when caring for such students and only somewhat more than one third were "very comfortable with everyday issues and emergencies." Some nurse respondents noted that parents did not always

disclose to them that their child had epilepsy, did not submit emergency contact forms and current medical information, or did not provide medications in a timely manner. The vast majority, over 80 percent, showed strong interest in learning more about caring for students with epilepsy. None reported receiving specific training in epilepsy, and the number of students each tracks is small.⁴⁷

Key informants saw lack of knowledge about epilepsy among families as an important barrier to care, noting that lack of understanding about variants of epilepsy not characterized by generalized seizures can delay diagnosis. Stigma and fear may also play a role, as may cultural and religious beliefs. In the focus groups, participants appeared to be more familiar with insurance than epilepsy. They were adept at using the system but showed evidence of some misconceptions about epilepsy. Many expressed a desire for more information, particularly about the causes of epilepsy.

Quality of care

The key informants were asked about coordination of care among providers, provider knowledge about epilepsy, and support for parents, as aspects of the quality of care. These issues also came up in the focus groups.

Care coordination: Key informants expressed strong reservations about the quality of care coordination. Some saw care coordinators as pre-authorizing agents only and saw primary care physician practices as better suited for well-child care than coordination of complicated cases such as epilepsy. Care coordination at HSCSN received “mixed reviews” from key informants who cited quality variation across coordinators. Focus group participants, on the other hand, were highly appreciative of the care they received and the help they got in navigating the system. They believed that they could call HSCSN, in particular, say what the problem was, and HSCSN would generally implement a solution. Caretakers of HSCSN members suggested that caretakers of non-HSCSN members join HSCSN to get better services and better coordination of services. Focus group participants noted that although there was more turnover among case managers than among service providers, the case managers were effective at providing continuity of care.

Provider knowledge: Some of the focus group participants had long-term relationships with physicians and nurse’s aides that they cherished, and they were especially complimentary of a particular provider at Howard University and of staff at Children’s Hospital (CNMC). Key informants and focus group participants alike were critical of the level of knowledge of emergency room providers. In addition, young adult focus group participants did not see school nurses as having enough knowledge and experience with epilepsy to help them at school.

Parent and community support and education: As noted above, key informants thought that parent knowledge about epilepsy and use of the health care system were barriers to care. In the focus groups, it was clear that caretakers and young adults both needed and wanted additional information about their condition. Most participants, however, appeared quite adept at navigating the health care system. One exception was the mother of a child relatively recently diagnosed with epilepsy who was still, after two years, trying to get all the services she felt her child needed. Her difficulties suggest that experience is a good teacher but that the newly diagnosed might need additional attention

and support. There were apparent differences across MCOs in ease of getting needed services, although the differences in length of time in the MCO is a possible confounding factor.

The literature supports the notion that children in families with strong support are likely to have better outcomes.⁴⁸ The caretakers focus group was characterized by genuine pleasure at being able to discuss their children's problems with other caretakers, suggesting peer support as a gap in services for parents.

Working with District government agencies

The literature stresses the importance of a strong administrative home for services for children with special health care needs, such as epilepsy.⁴⁹ It suggests establishing interagency agreements for coordinating needed services across providers and agencies (schools, physical health providers, mental health providers), and promotes shared record keeping, family involvement, and a focus on outcomes. Key informants expressed enthusiasm for the Department of Health's epilepsy project. However, some found the Department fragmented, which made it confusing to work with. There were calls for naming one point of contact at the Department for matters pertaining to pediatric epilepsy and for greater collaboration between the Department and private agencies and providers working on epilepsy.

Transition services

Transitions occur at several points in a child's tenure on Medicaid—from early childhood services to school-based services to services for adults. Key informants identified problems at each transition point. Eight of the ten key informants expressed frustration at the lack of transition services in the District. CNMC has a coordinator for transition services (youth to adult care); he says that he is the only person in the District coordinating transitions and that there needs to be more such staff. In contrast, focus group participants had not given much thought to the transition to adult services. Their lack of knowledge of the possible challenges of the impending transition could be taken as evidence of the lack of transition services since most were aware of services available to them. Their generally high level of confidence in their care coordinators and providers seemed to extend to transition as well. They expressed their belief that caseworkers and primary care physicians would take care of whatever was necessary. Both mothers and young adult participants felt lucky to live in the District where their needs were taken care of, and they expected that the government would and should continue taking care of them as they moved to adult services.

Data issues

The data analysis under this project was hampered by a lack of consistent data on children and youth with epilepsy. The relatively new HIPAA privacy requirements seem to have made custodians of data reluctant to share any of the information they collect. Consistent basic demographic data was difficult to identify, and information on treatment patterns, particularly drug regimens, was not readily available. Tracking children across MCOs and on-and-off Medicaid was not possible due to lack of standard identifiers. Such information is critical for helping to improve access to and utilization of care for this population.

One key informant noted a different data gap, that of information on children before age three. She reported that although information on children with special health care needs is transmitted from hospitals to the Department of Health, it is not then made available to programs that offer outreach to such children. Better outreach to a group at high risk could result in earlier identification and treatment of very young children with epilepsy.

HOSPITALIZATIONS OF MEDICAID CHILDREN AND YOUTH WITH EPILEPSY

Epilepsy is considered a condition for which hospitalization generally may be avoided if adequate primary care is received.⁵⁰ Three recent studies on avoidable hospitalizations, widely referred to as studies of ambulatory care sensitive conditions, included epilepsy in their analyses.⁵¹ On the premise of this research, we used DC hospital discharge data to determine if children ages 0 to 21 years enrolled in Medicaid have a higher rate of admission to the hospital for epilepsy than their non-Medicaid peers, which could indicate problems or deficiencies in their primary care. We compared admissions for epilepsy/convulsions and febrile seizures for the 749 Medicaid and non-Medicaid admissions to District hospitals between 2000 and 2004.⁵²

Table 2 (next page) shows summary statistics on hospital admissions for epilepsy and convulsions. Epilepsy admissions occurred disproportionately among the younger children in the study population. Because the incidence of epilepsy is highest among children under age two (and individuals over age 65),⁵³ it is not unexpected that hospitalizations are high for this age group. There is also evidence from the literature that children who are younger and present with epilepsy at the hospital emergency room are more likely to be admitted than are older children.⁵⁴ Nearly 60 percent of admissions were for males. Incidence of epilepsy has been found to be somewhat higher in males, perhaps up to 20 percent higher.⁵⁵ However, the elevated incidence does not fully explain the excess, by a factor of 1.46, of male admissions over female admissions observed in our data.

Almost half of all admissions were for one day, with no difference seen between Medicaid and non-Medicaid patients. Analysis of charges reported for intensive care, laboratory, pharmacy, and radiology, show that Medicaid patients were less likely to have a charge for these services than were non-Medicaid patients. The available data do not suggest a reason for the differences but they might be due to a difference in severity of epilepsy between the two populations, differences in treatment patterns at hospitals that treat more Medicaid patients, or differences in the treatment of patients with different insurance coverage.

In table 3 (following page), we compare admission rates for Medicaid and non-Medicaid children for epilepsy/convulsions as compared with admissions for febrile seizures. Admission rates for epilepsy are considerably higher among Medicaid enrollees than others. The five-year cumulative rate for epilepsy admissions of Medicaid enrollees was 12.4 per 10,000, compared with 8.2 per 10,000 for the non-Medicaid population, a difference of about 50 percent. The admission rate for febrile seizures is also higher among Medicaid enrollees, 1.6 versus 1.1 per 10,000. The percentage difference between the two rates, however, is lower—35.9 percent—than that for epilepsy.

Table 2

Summary Statistics on Hospital Admissions for Epilepsy (345) and
Convulsions (780.39) for Medicaid vs. Non-Medicaid Enrollees in DC
(ages 0-21)

Federal Fiscal Years 2000-2004

	TOTAL		MEDICAID		NON-MEDICAID	
TOTAL ADMISSIONS	749	100.0%	454	100.0%	295	100.0%
Age						
Less than 1 year	79	10.5%	49	10.8%	30	10.2%
1 year	81	10.8%	46	10.1%	35	11.9%
2 - 5 years	181	24.2%	120	26.4%	61	20.7%
6-10 years	171	22.8%	116	25.6%	55	18.6%
11-15 years	120	16.0%	78	17.2%	42	14.2%
16-21 years	117	15.6%	45	9.9%	72	24.4%
Gender						
Female	304	40.6%	184	40.5%	120	40.7%
Male	445	59.4%	270	59.5%	175	59.3%
Race						
Asian or Pacific Islander	3	0.4%	1	0.2%	2	0.7%
Black	584	78.0%	396	87.2%	188	63.7%
White	51	6.8%	6	1.3%	45	15.3%
Other	87	11.6%	46	10.1%	41	13.9%
Unknown	24	3.2%	5	1.1%	19	6.4%
Length of stay (days)						
1	357	47.7%	217	47.8%	140	47.5%
2	197	26.3%	119	26.2%	78	26.4%
3-5	146	19.5%	88	19.4%	58	19.7%
6+	49	6.5%	30	6.6%	19	6.4%
Patients with charges during stay						
ICU (any amount)	84	11.2%	37	8.1%	47	15.9%
Surgery (\$1,000+)	7	0.9%	5	1.1%	2	0.7%
Lab (any amount)	234	31.2%	129	28.4%	105	35.6%
Pharmacy (any amount)	216	28.8%	123	27.1%	93	31.5%
Radiology (any amount)	185	24.7%	101	22.2%	84	28.5%
Payer						
Commercial	202	27.0%				
DC Medicaid	454	60.6%				
Medicare	6	0.8%				
Other Public	37	4.9%				
Self-Pay	28	3.7%				
Other/Unknown	22	2.9%				

Data Sources: DC Hospital Discharge Dataset, federal fiscal years 2000-2004

Table 3

Rate of Epilepsy and Convulsions (345 and 780.39) vs. Febrile Seizures (780.31) for Medicaid vs. Non-Medicaid Enrollees in DC (ages 0-21)

Federal Fiscal Years 2000-2004

Total Admissions	
Epilepsy/convulsion admissions >=21	
Total	749
DC Medicaid	454
Other	295
Febrile seizure admissions >=21	
Total	98
DC Medicaid	57
Other	41
Admission Rates	
Rate of epilepsy/convulsion admissions per 100,000	
Total	103.3
DC Medicaid	123.9
Other	82.4
Rate of febrile seizure admissions per 100,000	
Total	13.5
DC Medicaid	15.6
Other	11.4
Percent difference between Medicaid vs. Non-Medicaid	
Rate of epilepsy/convulsion admissions per 100,000	50.4%
Rate of febrile seizure admissions per 100,000	35.9%

Source: DC Hospital Discharge Dataset, federal fiscal years 2000–2004.

These results could suggest possible insufficiencies in ambulatory care services for Medicaid patients that lead to an excess of avoidable hospitalizations. The insufficiencies might reflect difficulties in primary care access by Medicaid enrollees, inadequate experience with epilepsy among primary care providers, inadequate access to epilepsy specialists, or poor patient compliance with recommended treatments. Other possible explanations include a greater acuity of disease and more comorbidities among low-income persons⁵⁶ and longstanding patterns of emergency room use by Medicaid enrollees.⁵⁷ There is also some evidence in the literature that hospitalizations for epilepsy are higher among lower income populations.⁵⁸

SUMMARY AND RECOMMENDATIONS

The various sources of information tapped for this needs assessment provide an inconsistent picture of the care available for Medicaid children and youth with epilepsy in the District. The analysis of hospital admissions suggests an imperfect ambulatory care system. However, from the perspective of young adults and their caretakers, who see the system through the lens of their own illness and experience, the services available in the District, though not perfect, are a godsend, for which they are grateful. From the perspective of key informants, who see the system as it could be, there are frustrating gaps and failings. There is some truth in each of these points of view. The care available to children and youth with epilepsy is meeting many of the needs of this population. With some work, it could meet more of the needs more efficiently. In this section, we provide recommendations related to specific goals identified by the Department of Health under this project that could contribute to better care.

Goal: Achieve early detection, diagnosis, and treatment of epilepsy

Early detection and diagnosis: Given the importance of early treatment for epilepsy, the identified problems in this area are particularly important to address quickly and effectively. Epilepsy comes in many forms. The more severe forms are likely to be readily diagnosed, while the less severe forms are often missed. Early detection requires getting information about epilepsy in all of its various forms to people dealing with young children. This group includes parents, child care providers, and school nurses who might be the first to notice abnormalities. Primary care providers and their office staffs need enough information not only so they can identify children with epilepsy and refer them to appropriate specialists but also so they can be a source of information to parents.

RECOMMENDATIONS

- Survey primary care providers about needs for continuing education in early diagnosis of epilepsy, and identify or develop appropriate educational tools.
- Develop educational materials on the early and varied signs of epilepsy for child care providers, school nurses, and others with responsibilities for young children.
- Develop educational materials and programs for parents, who are likely to be the most attentive observers of their children. Materials should be available in many forms—written, audio, and visual—and designed for specific ethnic, cultural, and language target groups to provide both information and support.

Treatment of epilepsy: While the families with children with epilepsy contacted for this study had very few complaints about the care they receive, key informants identified gaps in care. Reports of difficulties getting neurology appointments in spite of a high number of pediatric neurologists in practice in the District suggests that supply might not be the only obstacle to care. Financial issues, such as reimbursement rates

under Medicaid, and process issues, such as administrative requirements for referrals that are seen as burdensome and that vary across MCOs, are likely contributors and may be more directly addressed than the supply of providers.

Two groups of providers were identified as less than optimally knowledgeable about epilepsy—school nurses and emergency room staff. Both of these groups could be important sources of care and/or support for children and youth with epilepsy.

The excess of avoidable hospital admissions for epilepsy/convulsions supports the contention that there are deficiencies in care. However, the analysis could not determine whether the deficiencies were related to problems in the delivery of ongoing care or to compliance by patients and their families with prescribed regimens. Further assessment of this issue could identify possible ameliorative action.

The literature recognizes the high prevalence of mental health issues among children and youth with epilepsy. Focus group participants also identified non-medical problems in dealing with their or their child's illness and associated comorbidities. Greater attention to the psychosocial issues could lead to improved functioning for this population, particularly as they become adults.

RECOMMENDATIONS

- Undertake a study of hospital admissions for epilepsy/convulsions to identify patterns among providers, MCOs, patients, prescribed medications, referral requirements, or other factors that could be susceptible to remediation.
- Survey primary care providers to determine the barriers that they face in treating children and youth with epilepsy.
- Survey specialists to determine caseloads and to identify any barriers to accepting Medicaid clients.
- Consider instituting a system of referral rotation and/or assignment to ease burdens on participating providers and to more evenly distribute caseloads.
- As needed to address barriers thus identified, design culturally appropriate educational materials for patients and their caretakers on the causes of epilepsy, treatment regimens, side effects, and the need for compliance; revise formularies and/or provisions for exceptions to formularies, design continuing education materials for providers and their staff, revise referral requirements, or other identified interventions. Particular attention should be given to developing materials for caretakers of children newly diagnosed with epilepsy.
- Identify appropriate training for school nurses and ensure that all nurses in schools where there are children with epilepsy have received it. Such training could be phased in over time, if necessary, and refresher courses provided, as needed.
- Develop and/or implement treatment protocols for use by emergency room staff when a child presents with a seizure. The protocol should include

notification of the child's primary care provider and neurologist to promote coordination of care.

- Investigate successful models in other jurisdictions for addressing the psychosocial issues associated with epilepsy for children, youth, and their families.

Goal: Improve access to a medical home

The medical home model of care is particularly well-suited to children with special health care needs, such as those with epilepsy. It involves providers working with families to ensure that the medical and non-medical needs of children are met.⁵⁹ The District's HSCSN uses an intensive version of the medical home concept, and many of the District's children and youth with epilepsy are HSCSN members and have felt well-served. Studies show the importance of its case management services, wraparound services, and reimbursement strategy.⁶⁰ The District should build on the success of this model.

Key informants and the focus group results both suggest that more attention needs to be given to coordinating transitions among different levels of care, various sites of care, and different coverage programs. The medical home model for epilepsy should explicitly address the issues of care coordination and transitions between programs, at both the systems level and the client level.⁶¹

RECOMMENDATIONS

- Work to increase the number of children and youth with epilepsy served by medical homes designed for this population. This expansion could be accomplished by directing children with epilepsy to established programs, such as HSCSN, or by promoting comprehensive care programs for children and youth with epilepsy within other Medicaid MCOs and at other primary care sites.
- Work to continually improve the care provided in medical homes through establishing a medical advisory group to review treatment models, as proposed in the project document, or providing continuing education for providers and staff at medical homes.
- Establish a tracking mechanism, such as a registry, for children and youth with epilepsy so that they can be directed to the medical homes that can best meet their needs.
- Use the tracking mechanism to ensure that children and youth continue to receive needed care from providers knowledgeable about their condition as they move around the health care system, including moving onto and off of Medicaid.

- Assign responsibility to one Department of Health office for the coordination of transitions for children as they age in the system, with particular attention to newly diagnosed children of all ages entering the system, entry into school or other educational programs, and transition to adult services. Identify appropriate roles for the Department, primary care providers, specialists, family and the patient.

Goals: Address the stigma associated with epilepsy

Identify and address the language and cultural barriers in MUAs⁶²

Focus group participants spoke eloquently and passionately about the difficulties of having a condition that so few people understand and about which there are so many misunderstandings. Key informants noted the existence of cultural differences in the way that epilepsy is viewed. Even among the staffs at schools and medical institutions, there is a recognized lack of understanding about how to support children and youth with epilepsy. There are many situations that would be improved by better understanding of the condition, its causes, and how to support children and youth who have it.

RECOMMENDATIONS

- Develop targeted education campaigns for a wide range of groups including primary care provider staff, emergency department staff, school nurses, school principals, and teachers.
- Consider including an explanation of epilepsy in school health and wellness curricula, with increasing sophistication in later grades.
- Identify specific cultural or religious interpretations of epilepsy that might be harmful to children with epilepsy and design culturally appropriate interventions to address them for such groups as churches, parent organizations, community groups, and youth groups.
- Work with community groups to promote a better understanding of epilepsy, while encouraging community leaders to help identify children with epilepsy and provide support for their families.
- Provide specific training for providers of services for non-English speakers to promote a better understanding of epilepsy, taking into account not only the differences in language but also the different cultural beliefs about the condition.

Goal: Develop and implement strategies for sustaining systems change

Change is an iterative process that requires monitoring and adjustment to keep it on track. Two factors are critical for sustaining systems change—accurate and timely data on outcomes and processes of interest and a forum for interpreting the data and acting on the findings.

The availability of data was an issue for the needs assessment; just identifying children and youth with epilepsy was difficult. Better data would allow tracking of epilepsy-related morbidity and mortality. The first step, however, is a well-defined population. A registry of children and youth with epilepsy formulated using a standard definition is a critical first step in assessing the effectiveness of the system designed to treat these children. The registry could be centrally maintained, that is, at the Department of Health, rather than at the MCOs, so that the population could be followed even with “churning” due to changes in eligibility, change of domicile to outside the District, and change in MCO.

RECOMMENDATIONS

- Identify an office at the Department of Health with responsibility for care for children and youth with epilepsy to monitor system change.
- Establish a standard definition of a child or youth with epilepsy. Then, establish conventions on the collection of data on children and youth with epilepsy (who collects the data, what data are collected at what intervals, and how data are reported and to whom). Data elements and conventions should be designed to reflect the changes that the Department wants to track.
- Collect baseline data against which change can be measured and establish a central data repository.
- Identify outcomes and process measures, and track patterns of care to identify gaps in access or other problems in utilization.
- Establish an advisory committee that meets at designated intervals to discuss progress, identify bottlenecks, and propose remedial actions, where needed.

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