Caring for Children With Special Healthcare Needs in the Managed Care Environment

Michelle R. Hawkins, MSN, MBA, RN, CCM, Beth Diehl-Svrjcek, MS, RN, CCRN, NNP, CCM, LNCC, and Linda J. Dunbar, PhD, RN

Dramatic medical and technological advances over the past 15 years have resulted in the survival into adulthood of children with chronic health conditions. As this population subset has increased, the demand of caring for these children in the managed care arena has become challenging from a clinical, fiscal, and member satisfaction perspective. A disease management program was designed for children, ages birth through age 18, identified as having special needs at the time of birth or at any point throughout childhood related to disease processes such as diabetes, sickle cell disease, genetic aberrations, or the multiple complications of extreme prematurity. Components of the program included identification of the population, coordinated risk assessment, and ongoing case management interventions. Most important, outcome indicators were tracked to demonstrate program effectiveness. The formulation and function of a dedicated disease management database is also discussed.

The past two decades have witnessed tremendous medical and technological advances in pediatric and neonatal medicine. New patient care methodologies resulting from research and evidence-based practice, utilized from birth through the adolescent years, have resulted in a population of children with special healthcare needs who would not have previously survived. Healthcare systems, especially managed care companies, are challenged to provide appropriate, timely, and cost-effective services for these children and their families. A definition by the Maternal Child Health Bureau provides a framework of reference:

Children with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type and amount beyond that required by children generally. (McPherson et al., 1998, p. 137)

Administrative Entity

Johns Hopkins HealthCare (JHHC) is a limited liability company administering both commercial and Medicaid health plans under the Johns Hopkins Health System umbrella. The company has three lines of business. The largest member enrollment, approximately 120,000 lives, is Priority Partners, a Maryland Medicaid Managed Care Organization. The second population is the Uniformed Services Family Health Plan (USFHP), a Department of Defense sponsored managed care plan, offered to eligible military retirees and their family members, and active duty family members, through Johns Hopkins. The third line of business is a commercial insurance line known as EHP or Employer Health Programs.

Challenged with cost-containment inherent within the managed care environment, JHHC developed a

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Address correspondence to Michelle R. Hawkins, MSN, MBA, RN, CCM, Johns Hopkins HealthCare, LLC, 6704 Curtis Court, Glen Burnie, MD 21060 (mhawkins@jhhc.com).
children with Special Needs Disease Management Program in December of 2000. This program serves the Priority Partners and USFHP lines of business only, with the goal of providing comprehensive disease management to a defined population and documenting outcomes from a fiscal, clinical, and satisfaction perspective. All data are housed in a specially designed disease management database.

The program is guided by the principles of the Disease Management Association of America (DMAA). This organization defines disease management as “a system of coordinated healthcare interventions and communications for populations with conditions in which self-care are significant” (DMAA, p. 1). Accordingly, the DMAA cites the support of the practitioner/patient relationship and plan of care, and emphasizes prevention of exacerbations and complications utilizing evidence-based guidelines and patient empowerment strategies. Finally, DMAA evaluates clinical, humanistic, and economic outcomes on an ongoing basis with the goal of improving overall health. Incorporating these principles is the objective of the Children with Special Needs Disease Management Program.

**Development Phase**

The initial diagnostic criteria for referral and enrollment are as follows:

- Juvenile-onset diabetes (type I or II)
- Sickle cell disease
- Complex congenital heart disease
- Neurological devastation (hypoxic ischemic encephalopathy, intraventricular hemorrhage)
- Genetic syndromes (trisomy 13, 18, or 21)
- Multiple comorbidities (extreme prematurity, failure to thrive, gastroesophageal reflux disease, retinopathy of prematurity, chronic lung disease)

Identification of members is sought through multiple avenues. Claims reports are queried by International Classification of Diseases-9 (ICD-9) codes reflecting the above diagnoses. Additional internal JHHC departments are educated regarding the program and advised to refer to the program if a contact made by the family or primary care provider (PCP) warrants further investigation. Examples of this include a request for costly durable medical equipment (DME), for example, motorized wheelchair or a high-end pharmaceutical agent. Externally, high-volume pediatric clinics in the Baltimore metropolitan area, PCPs, and inpatient pediatric case managers at Johns Hopkins Hospital and related entities are made aware of the program’s existence to promote the referral base.

Although a diagnostic criterion is the main driver, other criteria for enrollment that could lead to high costs are also defined and include the following:

- Need for shift nursing services in the client’s home. This is often the case when a child has a benefit through a secondary commercial insurance carrier in addition to Maryland Medicaid coverage. However, the commercial carrier may not have a benefit that covers the cost of shift nursing; therefore, Medicaid benefits are utilized. No subacute facilities exist in the state of Maryland for long-term care; therefore, these children must be cared for in the home environment and Medicaid becomes the payer of default.
- Involvement of three or more subspecialty providers reflective of a complex medical condition.
- Two or more emergency department (ED) encounters within the past 12 months, tracked via a specific ED database.
- Significant developmental delay as identified by an Infants and Toddlers Program or pediatric specialist. This population often encompasses neonatal intensive care unit graduates with multiple comorbidities or a child with a genetic syndrome.

Exclusion criteria for the program include mental illness, specifically because mental health benefits are carved out for Maryland Medicaid recipients and coordinated through a separate agency. Any child with extensive rehabilitative needs arising primarily from a traumatic event such as a motor vehicle accident or bicycle accident versus a chronic illness scenario is another example of exclusion. Children with cancer are excluded from the program as they are often prescribed regimented chemotherapy treatment protocols; therefore, the ability to control costs within the managed care environment is somewhat limited.

**Start-Up Phase**

Various program initiatives were undertaken in the start-up phase. A brochure highlighting the specific program elements was developed with the assistance
of a graphic arts company and distributed to providers and possible referral sources. Work was undertaken with the information services, an internal JHHC department, to identify critical elements for a dedicated database so that all clinical data could be effectively tracked. A medical consultant actively practicing in the greater pediatric community was secured to provide the team with ongoing clinical advice and support. This consultant complemented a full-time medical director employed directly by JHHC but without pediatric expertise. In concert with the medical consultant, program goals were established and tied closely to the desired clinical outcomes.

Appropriate nurse case manager staffing is required to achieve positive health and wellness outcomes. The program was originally staffed with two full-time equivalents (FTEs) and over the course of 5 years expanded to a staff of five FTEs with an advanced practice nurse case manager who served as the clinical lead for the program. All of the case managers are required by job description to possess at least 5 years of clinical experience, three of which should be pediatric in origin. As such, role functions include a face-to-face and/or telephonic assessment of the client/family unit to develop a plan of care to meet short- and long-term goals. When evidence-based criteria were available, the plan incorporated these criteria on the basis of the child’s diagnosis. Coordination, communication, and collaboration are expected to serve the best interests of the client/family.

The last and, perhaps, the most important defined role function is that of advocacy. Given the majority of the population is Medicaid based with a lifestyle often reflective of poverty-level conditions, a respect for beliefs, value systems, and confounding socioeconomic factors are imperative to develop an effective working relationship with the family unit.

**Referral Process**

Once the referral is received through various avenues, both internally and externally, the case management assistant performs several administrative tasks. First, she verifies the member’s eligibility status with JHHC via the enrollment system. The case is then entered into a database known as Case Finder. The Case Finder database serves all of the disease management programs within JHHC and tracks each member’s enrollment by program, assigned case manager, and program status, that is, open, closed, pending, or unmanaged with a corresponding date. After these two steps have been completed, an introductory letter is sent to the PCP as well as to the parent or guardian of the child. If the PCP does not desire the patient to receive case management services, he or she is given 5 business days in which to decline. Given that situation, the case is not opened.

After all administrative steps are completed, the case is assigned to the geographically based case manager so that an initial contact can be made. In most instances, this initial contact is telephonic in nature but it can be in-person at the home of the family or at a pediatric clinic or the pediatrician’s office. From a logistical perspective, the strategic geographic distribution of the case managers across the state of Maryland allows them to become accessible to their local pediatric community. Therefore, pediatricians, clinics, and community agencies have an established point person for ongoing contacts, which is beneficial because the case managers actually work where they reside.

**Initial Member Assessment**

When the nurse case manager initially contacts the parent or guardian of the child, he or she confirms demographic information as well as the primary caretaker, and any subspecialty providers. Interpreters are available if a language barrier exists between the case manager and the family. An inventory is taken of current medications, DME, and amount and type of home health services in addition to school and community services that are in place to determine whether changes need to be made. Since JHHC maintains an internal provider relations database, a PCP or subspecialist can be easily located, if one is lacking or inappropriate, by line of business, specialty, county, or ZIP code of residence. Occasionally, the family may have been utilizing an out-of-network provider for DME or home health; therefore, transition to an in-network provider is sought. Before the initial contact is concluded, the case manager has determined the critical issues for the family/child related to providers and various services.

**Parent Contact Logs**

For ongoing contacts with the family, and to provide standardization within the program, parent contact logs are utilized by the case management team for the high-volume diagnoses of diabetes, obesity,

<table>
<thead>
<tr>
<th>TABLE 1 Parent Contact Logs/Diabetes</th>
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<tbody>
<tr>
<td>General status of child</td>
</tr>
<tr>
<td>Blood sugar trends</td>
</tr>
<tr>
<td>Hemoglobin A&lt;sub&gt;1c&lt;/sub&gt;</td>
</tr>
<tr>
<td>Insulin requirements</td>
</tr>
<tr>
<td>Diet Issues</td>
</tr>
<tr>
<td>Physical activity/exercise</td>
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<tr>
<td>F/U appts/consults</td>
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<tr>
<td>School/behavioral issues</td>
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premature infant, and sickle cell disease. These logs are a basis for discussion during every contact with the child and the family. For children with diabetes, parents are asked the general status of the child, blood sugar trends, hemoglobin A1C levels, current insulin requirements, diet compliance, amount of physical activity and exercise, scheduled follow-up appointments, and finally any school and behavioral issues (Table 1). The logs for each diagnosis are tied closely to the tracked clinical outcomes for each medical condition so that the case manager can ascertain that information on an ongoing basis.

For an obese child, every contact seeks information regarding the general status of the child, physical parameters related to weight and body mass index, diet regimen, amount of physical activity/exercise, and appointments. For the families of premature infants, again, the general status is questioned, along with current medications, administration of Respiratory Syncytial Virus prophylaxis, nutritional status, well-child care, follow-up appointments, and Infant and Toddler Program interventions. For sickle cell disease, general status, medications, especially penicillin prophylaxis, immunizations, ED visits/hospital admits, recent blood transfusions, follow-up appointments and consults, and school and behavioral issues comprise the list of case manager inquiries.

**Levels of Care Intensity**

To assure an equitable distribution of caseload among the case managers, levels of care intensity are established (Table 2). When the program was initiated, only three levels of case management intensity existed. Level I cases represented a newly opened case or a case in an acute crisis situation resulting in daily or weekly contact. Level II required twice a month contact, and Level III was a minimal monthly contact. However, because of the chronicity of some of the children enrolled, a fourth level is in place, which allows a minimum of a quarterly contact with the member. This additional level provided more leeway for each case manager in terms of his or her caseload. A specific level of care is updated weekly by the case manager according to contact frequency. The program director has direct access to this caseload information and is able to compile weekly productivity reports for the Children with Special Needs Disease Management Program to meet organizational targets.

**Care Plans**

The program has standardized care plans housed within the Children with Special Needs database with listed problems, goals, and interventions. These problems specifically relate to episodic case management measured by information obtained from parent contact logs and addresses compliance, that is, PCP or specialty provider visits attended. Any ED visit and/or hospital admit is carefully tracked for appropriate use for a particular disease process. Nutrition, an extremely important issue for a special needs child, is carefully evaluated. The goal is to maintain the child’s physical growth between the 5th and 95th percentile on standardized growth charts. Parent and child education of the specific disease process is queried for baseline understanding and what immediate knowledge deficits exist. The degree to which the specific goal is met is measured by percentage, in increments of 25, 50, 75, and 100%. On a monthly basis, the case manager records in the Children with Special Needs database what percentage of each goal has been met.

**Clinical Outcomes**

Clinical indicators are established for diabetes, sickle cell disease, and prematurity so as to provide clinical credence to the program. These specific diagnoses were chosen because of high-volume member enrollment. The three items tracked for the children with diabetes are hemoglobin A1C, micro albumin level, and annual eye exams (Table 3). For children with sickle cell disease, penicillin prophylaxis and pneumovax/prevnar administration are closely monitored. Finally, for former neonatal intensive care unit graduates, Respiratory Syncytial Virus prophylaxis, utilization of premature formula for the first year of life, and enrollment in the Infants and Toddlers Program are the designated clinical targets.

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**TABLE 2**

Levels of Care Intensity

- **Level I**—Newly opened case or case in acute crisis situation resulting in daily or weekly contact
- **Level II**—Twice a month contact
- **Level III**—Monthly contact with member
- **Level IV**—Quarterly contact with member

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Clinical indicators are established for diabetes, sickle cell disease, and prematurity so as to provide clinical credence to the program.
TABLE 3
Clinical Outcomes/Diabetes

- Hgb A1c
  - < 7 tracked every 3–6 months
  - monitor % of children with most recent > 9.5%
- Microalbumin in level < 30 mg/dl of Creatinine
  - tracked annually for children diagnosed > 5 years with Type 1
  - Type II at time of diagnosis then annually
- Annual eye exam for retinopathy

**DATA SUPPORTS**

Two separate database systems are used on a daily basis by the team; they are housed and maintained by the Information Services Department of JHHC. Because of confidential health information, both databases are password protected. The Children with Special Needs database was created internally by the Information Services Department in conjunction with the nursing team (Fig 1). This database is composed of multiple screens that address general information, enrollment, program status, disease management, contacts/notes, providers, diagnosis, laboratory trends, medications, clinical indicators, immunizations, hospital/ED visits, eye exams, DME, care plans, consents, and claims information. This system is very user-friendly, using multiple drop-down menu boxes. Enrollment data are imported from a data warehouse to provide consistency with member identification numbers and other demographic information essential for family contact. Free text options allow the case manager to enter detailed notes from home visits or telephonic encounters. The database is queried for reports required to complete a formal program evaluation.

The second system is the Case Finder database (Fig 2), which tracks the member by first and last name, line of business, that is, Priority Partners or USFHP, assigned program, assigned case manager, and program status, that is, pending, open, closed, unmanaged, etc. As with the Children with Special Needs database, reports are generated to determine an individual case manager’s current caseload or previously closed cases. If a client has been enrolled in other disease or case management programs, that information is located in the Case Finder database.
A very important data element in the Case Finder database is the Adjusted Clinical Groups Predictive Modeling (ACG-PM) score. Per Weiner, Abrams, and Bodycombe (2003), Johns Hopkins University’s ACG-PM software uses historical claims information to estimate a person’s future medical resource utilization. Weiner et al. (2003) further define predictive modeling as “a process that applies existing patient data to identify prospectively persons with high medical need and are at risk for above average future medical service utilization” (p. 18). The basis for ACG-PM is ICD-9 diagnosis code data, pharmacy data, selected medical conditions, hospital-dominant conditions, a completed pregnancy marker, age, and gender. Prior utilization is not a factor in determining an ACG-PM score; therefore, the effects of physician practice patterns do not affect the score. All claims available for a population are inputted into the ACG grouper and each enrollee is assigned a risk score from 0 to 1, which represents the enrollee’s probability of being in the top 5% of total costs for the health plan in the following year(s). ACG-PM is an efficient method to predict a population’s future healthcare utilization and costs. Any member having an ACG-PM score of 0.8 or greater would likely benefit from case management services. Because this score is a component of Case Finder and is periodically updated, the assigned case manager tracks the ACG-PM score over time to determine whether the score is lessening while the member is under case management. The ACG-PM score is a recent addition to the Case Finder database; therefore, its true functionality is limited from a historical perspective.

**DEMOGRAPHICS**

From January 11, 2000, to January 1, 2005, 1,169 children were referred for case management in the Children with Special Needs Disease Management Program. Subsequently, 744 of these children were ultimately managed, 425 of them were not managed. From a gender perspective, there was a male preponderance of 55% versus 45% female. The greatest number of enrollees was infants, a total of 238, which represents 33%. The next largest group was children between the ages of 1 and 5 years for 200 enrollees, a representation of 28% (Table 4).
All geographical areas of the state of Maryland are served by the Children with Special Needs Disease Management Program. Because of JHHC enrollment concentrations, the highest numbers of children are located on Maryland’s Eastern Shore, which is a large and predominantly rural area, as well as the surrounding metropolitan areas of Baltimore City and Washington, D.C. In contrast to the Eastern Shore, the geographical areas of Baltimore City and Washington, D.C., are very densely populated. This presents differing challenges for the assigned case manager relating to care access, transportation requirements, availability of in-network subspecialty providers, and the presence of local community agency support. For example, on the Eastern Shore, in-network pediatric subspecialty providers are scarce, compelling the case manager to negotiate a letter of agreement for the services of an out-of-network provider. The distance between the client’s home and a major medical center is greater in a rural area; therefore, transportation costs are carefully monitored by the case manager.

**Program Evaluation**

After the program had been executed for 18 months, a formal evaluation was undertaken to determine member satisfaction and ascertain clinical and financial outcomes. Member satisfaction is determined by a parent survey sent to the family when the case is closed. The survey addresses overall availability of the case manager to the family, provision of educational materials, and degree of satisfaction with assistance of medical problems. The final question is whether case management was beneficial to their child. Unfortunately, the return rate on the surveys was only 10%, comprising an N of 32. However, the vast majority of families were satisfied with the services that they received (Table 5).

Financial outcomes were calculated for children enrolled in the Children with Special Needs Disease Management Program for more than 6 months as well as for the number of total program enrollees, regardless of their length of enrollment. Criteria for evaluation included hospital admits per member per year, the length of stay of the hospital admission per member per year, ED visits per member per year, and total costs per member per month. All costs showed a significant drop with the exception of ED visits (Table 6). One hypothesis of this increase was that the number of visits increased because members recognized the need to receive treatment in the ED at the early stages of a crisis and would then be able to avert hospital admittance. In addition, although visits went up, frequent ED utilizers dropped. Therefore, members were treated and released rather than treated and admitted with an overall decrease in repeat visits.

The last outcome is an examination of the Rare and Expensive (REM) Case Management Program. This program is a carve-out for Maryland Medicaid recipients. It enrolls members with a defined list of ICD-9 diagnostic codes. For children, it includes all of the major birth defects, such as gastroschisis, omphalocele, tracheoesophageal fistula, and diaphragmatic hernia; maternal HIV exposure at the time of birth; and cerebral palsy. If a child was referred to the Children with Special Needs Disease Management Program, all geographical areas of the state of Maryland are served by the Children with Special Needs Disease Management Program. Because of JHHC enrollment concentrations, the highest numbers of children are located on Maryland’s Eastern Shore, which is a large and predominantly rural area, as well as the surrounding metropolitan areas of Baltimore City and Washington, D.C. In contrast to the Eastern Shore, the geographical areas of Baltimore City and Washington, D.C., are very densely populated. This presents differing challenges for the assigned case manager relating to care access, transportation requirements, availability of in-network subspecialty providers, and the presence of local community agency support. For example, on the Eastern Shore, in-network pediatric subspecialty providers are scarce, compelling the case manager to negotiate a letter of agreement for the services of an out-of-network provider. The distance between the client’s home and a major medical center is greater in a rural area; therefore, transportation costs are carefully monitored by the case manager.

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Program but then was determined by the case manager to be eligible for REM, the case manager would facilitate that application process if the family was in agreement. Once the application was processed and the child became REM effective, the financial burden shifts from JHHC to REM, and the REM program will assign another case manager. The advantages of REM enrollment for the family are that referrals for subspecialty care through a primary provider are not necessary and the family can seek care for their child from any medical provider who accepts Maryland Medicaid. However, given those program elements, it is not mandatory for a family to accept enrollment in REM. When the Children with Special Needs Disease Management Program evaluation was completed, 29 children had been identified as REM eligible. All of the applications for these children were clinically accepted; however, five families declined enrollment. As such, a projected annualized savings of $527,300 for JHHC was based on the premise that 20 children would be disenrolled from JHHC into REM annually (Table 7).

**CONCLUSION**

In summary, the formulation, design, and implementation of the Children with Special Needs Disease Management Program is demonstrating positive financial and member satisfaction outcomes. The structure and function of the program is reflective of the principles outlined by the DMMA and incorporates fairly new avenues of practice such as the ACG-PM score. Future initiatives will include the development of disease-specific educational packets for client/family education and further development of the advanced practice role as a clinical leader, researcher, and outcomes specialist.

**REFERENCES**


Michelle R. Hawkins, MSN, MBA, RN, CCM, is the Director of Care Management at Johns Hopkins HealthCare and a certified case manager. She received a BS from Howard University and a BSN from the University of Maryland. She completed the Business of Nursing Certificate Program and received her MSN/MBA at the Johns Hopkins University.

Beth Diehl-Svrjcek, MS, RN, CCRN, NNP, CCM, LNCC, is a consultant at Johns Hopkins HealthCare. She formerly served as the advanced practice nurse for the Special Needs Child Disease Management Program. She received a diploma from Hurley Medical Center School of Nursing, a BSN from the University of Michigan, and an MS and post-masters NNP certificate at the University of Maryland.

Linda J. Dunbar, PhD, RN, Vice-President of Care Management at Johns Hopkins HealthCare, received a BS in nursing from Towson University and an MS and PhD in health policy from the University of Maryland. The topic of Dr. Dunbar’s dissertation was identification and risk adjustment in populations of children with special needs.

**TABLE 7**

<table>
<thead>
<tr>
<th>Total Costs</th>
<th>Member Months</th>
<th>PMPM</th>
<th>PMPY</th>
<th>Projected Annualized Savings**</th>
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<td>$2197.00</td>
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N = 29
*34 REM applications were submitted and all were clinically accepted. 29 children enrolled into REM over 18 month period, 5 parents declined enrollment
**Projected savings based on 20 children disenrolled into REM annually

Because this score is a component of Case Finder and is periodically updated, the assigned case manager tracks the ACG-PM score over time to determine whether the score is lessening while the member is under case management.