

Making the Future Bright for Chronically Ill Kids



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More than ever, children are suffering from chronic diseases, which can have significant consequences to society and our health care system. As children grow, these conditions carry into adulthood and may cause further complications.

The National Institute for Health Care Management (NIHCM) Foundation held a forum in October, 2000 for the public and private sectors to discuss efforts to improve care for children with chronic illnesses, and the interrelationship between nutrition and chronic disease.

The forum was part of a series entitled "Bright Futures and Managed Care," which NIHCM Foundation is conducting under a cooperative agreement with the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). This Action Brief summarizes key issues and discussion from the forum.

Opening Presentations

Gloria Weissman, Deputy Director, Division of Services to Children with Special Health Care Needs, MCHB (Welcome)

Susan Dentzer, Correspondent, The NewsHour with Jim Lehrer (Moderator for the Day)

Donald Orr, MD, Professor of Pediatrics, Nursing, Research, and Nutrition, Indiana University School of Medicine (Keynote Speaker)

Gloria Weissman opened the meeting and explained the efforts and goals of the MCHB division that affect children with special health care needs (CSHCN). Over the past 20 years, the MCHB has developed and is now implementing a new model of care for CSHCN: family-centered, comprehensive, community-based, coordinated, and culturally competent. In addition, a new, broad definition of children with special health care needs has been developed that is now widely accepted. The first national survey of CSHCN is being supported by HRSA and carried out by the National Center for Health Statistics (NCHS).

Working in partnership with states, families, communities, providers, and health plans, the Bureau created a ten-year action plan to implement a community-based system of services for CSHCN. "The plans are to put in place services that are universal for all children with special health care needs," said **Ms. Weissman**. This new initiative will be the basis of a companion monograph to Healthy People 2010 that presents the blueprint for organizing, financing and delivering services for CSHCN.

The action plan is organized around six performance measures:

- (1) all children with special health care needs will receive regular ongoing comprehensive care within a medical home;
- (2) all families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;
- (3) all children will be screened early and continuously for special health care needs;
- (4) services for children and their families will be organized in ways that families can use them easily for family-centered care;
- (5) families will participate in decisionmaking

"The plans are to put in place services that are universal for all children with special health care needs."

*-Gloria
Weissman*

“[Children with chronic conditions] need access to comprehensive, family-centered, culturally competent systems of care. . . They need care coordination, and they need access to specialists, including mental health.”

- Dr. Donald Orr

at all levels and be satisfied with the services they receive; and
(6) children will transition to all aspects of adult life, to adult health care, to work, to independence.

Formal roll-out of the Healthy People 2010 Companion Monograph on CSHCN and the Action Plan will take place at a *National Summit on Children and Youth with Special Health Care Needs*, scheduled for December 12 and 13, 2001 in Washington, DC. For more information about the summit, go to www.psava.com.

Susan Dentzer started the sessions by highlighting the change in health care needs of children over the past century, which has shifted from infectious diseases as the leading cause of death for the entire population to other, more chronic conditions. “The question that arises is will we have a concerted effort in this country to focus on chronic disease among the population, and particularly among children, that is of the magnitude of what we devoted to combatting infectious disease around the turn of the century,” Ms. Dentzer asked.

Chronic Health Conditions

Dr. Donald Orr explained the different ways that chronic health conditions can be characterized: chronic physical conditions; special health care needs; disabilities or functional limitations; and severe restrictions of activity. As he noted, the definition can have implications for research, policy and provision of services.

Conditions that last three months or longer are generally considered to be chronic. Children with chronic physical conditions define the broadest group and the largest number of individuals. Prevalence data has shown that approximately 30% of children have a chronic physical condition, 20% have special health care needs, and 7% are functionally limited. For adolescents alone, 20% have a chronic condition. As the number of conditions increase, the impact on children, families, schools, and the health care system is more pronounced.

Children with chronic conditions have more contact with the health care system, yet they are more likely to have perceived unmet health needs. **Dr. Orr** stressed that children with chronic conditions need a medical home. “They need access to comprehensive, family-centered, culturally competent systems of care. They need collaboration between parent, child, and providers. They need care coordination, and they need access to specialists, including mental health. The care really needs to be developmentally-based and continuous,” said **Dr. Orr**.

The scope of services is affected by the specific condition and the severity, in terms of the type of providers and specialists, medications, ancillary services available, and insurance status. All children with chronic conditions need insurance to provide access to care. Most have a regular source of care and insurance, usually through Medicaid and public services for children with special health care needs. But, they also need providers trained to handle their needs.

One of the most pressing challenges is caring for adolescents with special health needs, particularly how to help them transition into the adult system of care, how to train providers to care for this population, and how to identify resources for coverage. Adolescents are young adults who need to be cared for in an adult health care system, and they often need additional help transitioning to the adult system from both parents and providers.

Coverage for services is a major problem for some adolescents, particularly when individuals need multiple services from different providers. As CSHCN age out of services, parental coverage or public programs, they find themselves with no source of health coverage. This is often complicated by preexisting conditions.

Health care providers need to have a better understanding of chronic conditions, their prevalence, and their impact on children and society. As access to care improves, so too must the provision of care for children of all ages.

REAL LIFE EXPERIENCE WITH CHRONIC CONDITIONS

Michael Rich, MD, Assistant Professor of Pediatrics, Harvard Medical School, and Children's Hospital, Boston

Katherine Cowan and Lindsay Cowan

Lynne Reeves Griffin, RN, Children's Hospital, Boston

Assessing Chronic Diseases

Modern technology has led to great advances in health care, yet it can also create a system that detrimentally separates the once intimate relationship between doctors and patients. **Dr. Michael Rich** uses technology to mimic the tradition of "house calls," allowing physicians to be closer to their patients by observing them in the home environment and learning about the disease process, their living situations and their experiences.

Most people view the physician as the expert, but, in fact the real experts are those who live

with the disease. Through **Dr. Rich's** Video Intervention/Prevention Assessment (VIA) model, children with chronic conditions document the events of their lives using a camcorder, creating a tool with which providers and others can improve the care that the children receive. **Dr. Rich** believes that the process can improve effective communication between providers and patients.

Using VIA, **Dr. Rich** asks children with asthma to tour their living environments, including their homes, schools, work places, neighborhoods, and anywhere else they go on a regular basis. The children are requested to record their asthma self-management tasks, use of medications and peak-flow meters, and their medical visits. They are asked to turn on the camera daily and give personal monologues about their day and their disease. They also interview family members, teachers, and others who know the child well.

Comparing medical histories to video diaries, **Dr. Rich** found that 95% of the children did not identify factors that would precipitate their asthma in their environments, such as allergens, dust, mold, dander, cosmetics, fumes, and smoke. Eighty-nine percent of the

A Snapshot of Pediatric Asthma

- Asthma is a chronic disease caused by a combination of allergenic, genetic, environmental, infectious, and socioeconomic influences. It is triggered by allergies or stimuli in the environment.
- Over 5.3 million U.S. children less than 18 years of age suffer from asthma, and the rate of asthma in children less than 5 years of age has increased by 160% over the past 15 years.
- The asthma costs to the United States in 1998 were \$11.3 billion.
- Asthma accounts for 14 million ambulatory care visits per year and for one in six pediatric emergency visits.
- Nearly 25% of U.S. children live in areas that do not meet national air quality standards. African-American, Hispanic, and Asian/Pacific Islander children are also disproportionately represented in areas where ozone levels are unacceptable.
- Over 50% of U.S. schools have indoor-air-quality problems, which potentially diminish a child's health ability to learn.

Source: Raskin, Lauren. *NCEMCH Policy Brief: Breathing Easy: Solutions in Pediatric Asthma*. Arlington, VA: National Center for Education in Maternal and Child Health, February 2000.

“We have to bring knowledge of disease and management strategies to the fore so that [chronically ill children] have the tools they need to self-manage, because the reality is they are the ones who manage these diseases.”

- Dr. Michael Rich

“Living with diabetes is a bit like shooting at a moving target.”

- Katharine Cowan

children used medications inappropriately. Examples included self-discontinuation of medications and ineffective inhaler technique. One young girl with asthma, who had been taught many times how to use an inhaler, showed her father an incorrect method of use.

Looking at psychological response to chronic illness, **Dr. Rich** observed a high level of isolation from peers, because of either real or perceived limitations in the child's life. Over half of the participants produced more than four hours of footage showing them sitting alone watching television or playing video games. Many were depressed either because of the disease or the medication side effects. “Fear of dying is the elephant sitting in the corner of the room,” noted **Dr. Rich**.

Even before anyone viewed the videotapes, **Dr. Rich** observed measurable improvements in the children's asthma-specific quality of life and activity levels. When asked about their experience with VIA, over half reported improved symptoms and well-being on a subjective basis. They also reported knowing more about asthma and feeling more in control.

Dr. Rich envisions three major areas in which VIA's findings could improve care: (1) in developing medical management plans that are responsive and sensitive to the realities of patients' lives; (2) in educating providers about the needs of their patients and families and the realities of living with a chronic illness, as well as educating the general public to the realities of chronic conditions; and (3) in creating health care policies which empower and advocate for patients, allowing improved access to care, services, and information, and in developing appropriate health-care financing strategies. “We have to bring knowledge of disease and management strategies to the fore so that [chronically ill children] have the tools they need to self-manage, because the reality is they are the ones who manage these diseases,” said **Dr. Rich**.

Dr. Rich emphasized the importance of listening to children and understanding from them what their life with disease is like. Traditionally, parents have been the proxy for the child. Parents' views are important, but the child's understanding can be the most informative.

Living With Diabetes

Ten-year-old **Lindsay Cowan**, who has Type I diabetes, and her mother, **Katherine Cowan**, put a real face on diabetes by describing their daily life managing **Lindsay's** disease. Mrs. Cowan explained that both Type I and Type II (formerly called adult-onset) diabetes are on the rise in the pediatric population. Although the majority of research efforts focus on adults, pediatric diabetes research is increasing.

“Living with diabetes . . . is a bit like shooting at a moving target,” said **Mrs. Cowan**. At age 4, **Lindsay** was diagnosed with Type I diabetes, the rarer form that requires daily insulin injections. Lindsay's blood-sugar range must be kept within defined parameters to balance blood sugar level; otherwise she could have seizures or other complications. Teachers, friends, and family members are all vigilant about maintaining Lindsay's blood-sugar level. She checks her levels throughout the day, particularly before each meal.

Balancing blood sugar levels within the appropriate range is key to keeping diabetic patients healthy. It is the long-term, persistent incidence of high blood-sugar levels, however, that leads to the more serious complications. Those which are more common include kidney damage that can lead to kidney failure, heart disease, stroke, retinopathy resulting in blindness, nerve damage which requires lower-limb amputations, and impotence.

As an example of her experiences, **Lindsay** demonstrated her insulin pump, which gives her constant infusions of insulin and allows her to eat and drink more freely. She made it clear that diabetes is a very complicated disease that requires constant attention.

Bright Futures For Children With Special Health Care Needs

Lynne Reeves Griffin focused on some of the global concerns that doctors, health practitioners, and families face when managing the health care of children with chronic health conditions. She is developing the ***Bright Futures for Children with Special Health Care Needs*** guide in collaboration with MCHB

and the National Center for Education in Maternal and Child Health (NCEMCH).

The *Bright Futures for Children with Special Health Care Needs* guide presents health supervision guidelines for children and adolescents with chronic health conditions. “We need to look at specific issues for children with special health care needs...the nuances of their health promotion and to their health supervision,” said **Ms. Griffin**.

The Bright Futures guide will include an overview of the issues primary care providers should consider when working with families who have a child with special health care needs. Family centered primary care, navigating complex systems and nuances to the health care of CSHCN are just a few of the areas examined in *Bright Futures for Children with Special Health Care Needs*.

The book will also include case studies aimed at giving providers examples of how to apply the Bright Futures framework to visits with families and children coping with chronic illness or disabilities. A thorough appendix will guide providers to more information to make working with families easier and will give them critical information to pass along to families.

The draft book is being reviewed by a geographically and culturally diverse steering committee. **Ms. Griffin** expects *Bright Futures for Children with Special Health Care Needs* to be released in 2002.

TOOLS AND EVALUATION

John Neff, MD, Associate Dean and Professor of Pediatrics, University of Washington School of Medicine, and Director, Center for Childhood Chronic Conditions, Children’s Hospital and Regional Medical Center, Seattle

Christina Bethell, PhD, Senior Vice President, Foundation for Accountability (FACCT)

Peter West, MD, Associate Medical Director and Medical Director for Medicare, Premera Blue Cross

Nancy Swigonski, MD, Assistant Professor, Division of Adolescent Medicine, Community and General Pediatrics, Indiana University School of Medicine

Screening for Chronic Conditions

Dr. John Neff presented a unique model of using administrative data to track CSHCN, which can be used to develop medical management plans for these children.

The first step is to identify children with chronic conditions, which is necessary to do quality assurance or risk adjustments. Using Clinical Risk Groups (CRGs) and software developed by the 3M Corporation and the National Association of Children’s Hospitals and Related Institutions (NACHRI), administrative data is clarified to identify children and categorize them by level of health status. The CRGs will classify individuals by the presence of a chronic condition, the type of chronic condition, and the severity of the condition, as well as the presence of significant acute health conditions.

The concept uses claims data to develop a precise hierarchical model by assigning a child to a single, mutually exclusive group, then to one of nine health status groups, and then to a specific CRG and severity level if identified as chronically ill. Multiple chronic conditions can be tracked within the higher severity levels.

Using an example from the Northwest Medical Bureau in Washington, **Dr. Neff** explained that as individuals move up into the higher severity levels, there is a more reasonable number of children to track and manage. Through this process, a group of high service users can be identified and offered a medical management program. As those programs progress, more children can be tracked through the lower severity levels.

This model can be a powerful tool for health plans to track chronically ill children, where they are being served, and the treatment process, especially whether they have case management. “You can use these screener tools in very effective ways to be able to track [children with special health care needs] within the [health] plan,” said **Dr. Neff**.

“We need to look at specific issues for children with special health care needs...the nuances of their health promotion and to their health supervision.”

- Lynne Reeves Griffin

“You can use these screener tools in very effective ways to be able to track [children with special health care needs] within the [health] plan.”

- Dr. John Neff

“[Health plans] have a unique perspective that we can offer in addition to data sources to help researchers focus on questions that can be answered and put into effect.”

- Dr. Peter West

Quality of Care Measurement

As part of the Child and Adolescent Health Measurement Initiative (CAHMI), the Foundation for Accountability (FACCT) worked collaboratively with the National Committee for Quality Assurance (NCQA) and other organizations to develop tools for identifying and measuring quality of care received by CSHCN. **Dr. Christina Bethell** noted that these tools are being incorporated into HEDIS 2002, the measurement system developed by NCQA to assess quality of care in health plans.

As a part of HEDIS, the Consumer Assessment of Health Plans (CAHPS 2.0H) Child Survey assesses the basic aspects of quality of care for the general pediatric population, specifically communication with providers, access to care and receiving care. Starting with HEDIS 2002, the CSHCN component developed through the CAHMI will be integrated into CAHPS 2.0H Child Survey. This includes the CSHCN Screener to identify children with special health care needs, a set of 31 supplemental questions focusing on dimensions of care with particular relevance for CSHCN and an enriched sampling strategy to reduce the starting sample size necessary to obtain a statistically robust sample of CSHCN.

The CSHCN Screener, a 5-item screening tool, is used in the survey to non-categorically identify children who have special health care needs. The enriched sampling strategy uses administrative records and an ICD-9 code based algorithm to prescreen for a cohort of children with a higher likelihood of meeting the survey-based CSHCN Screener criteria. The starting sample for CAHPS survey is stratified to include random samples from both the general population and the group meeting the prescreen criteria.

Results from the survey-based screening tool (CSHCN Screener) make it possible to calculate the standard composites and ratings derived from the core CAHPS 2.0 Child Survey for children who do and do not meet the criteria of having a special health care need. In addition to the standard CAHPS composites, four new domains assess quality of care for CSHCN: access to prescription medicines; access to specialized services; family-centered

care; communication with school and day care; and coordination of care.

FACCT expects the new tools to increase quality information for CSHCN, improve efficiency of data collection, and maintain a source of current information on overall plan quality for children. Any increase in cost is expected to be marginal because the HEDIS 2002 version of the CAHPS 2.0H Child Survey is administered every two years rather than the previous annual requirement.

FACCT has worked with many health plans to use this new measure for quality improvement. FACCT is also working on applications of the CSHCN screener for other uses, such as point of enrollment and at the provider level. “Hopefully, these [screener] methodologies will create some consistency in how we identify and think about quality for children with special needs,” said **Dr. Bethell**.

Health Plan Partnerships

Many health plans work collaboratively with other organizations to improve quality of care for their enrollees. **Dr. Peter West** described two different research projects to improve health care for children in which Premera Blue Cross is a partner.

Premera Blue Cross is cooperating in the Quality of Care for Children with Chronic Conditions (QC4) program, which is funded by Agency for Healthcare Research and Quality (AHRQ) and being conducted by the University of Washington School of Public Health’s Department of Health Services. The purpose of this study is to describe insurance product and delivery system characteristics that correlate with elements of quality of care for chronic conditions.

The Pediatric Palliative Care Project, funded by the Robert Wood Johnson Foundation through a grant to Children’s Hospital and Regional Medical Center, is a demonstration of how to provide flexible insurance benefits, in particular, hospice services, to care for children who are dying. In addition, the project seeks to apply an innovative tool that case managers can use with clinicians, care managers, and

others to establish appropriate goals of care for children with life-threatening illnesses.

When this program began, Premera Blue Cross had been working to develop flexible ways of applying benefits through the use of case management. This project brings together case managers from the insurer and the source of home care like hospice.

Dr. West noted that it is important for a health plan to get involved in these types of efforts in the early stages. Premera Blue Cross participated on advisory committees to help refine the proposals. Insurers are critical partners not only to supply crucial data, but also for advice and expertise. “[Health plans] have a unique perspective that we can offer in addition to data sources to help researchers focus on questions that can be answered and put into effect,” said **Dr. West**.

Dr. West suggested that health plans interested in collaborating in these types of projects establish simple processes to consider external proposals, and be prepared to continue working on dedicated research programs that run for a long period of time.

Public Health Realm

Reviewing research on the effect of health insurance to access and receipt of care for CSHCN, **Dr. Nancy Swigonski** noted that health insurance, public or private, improves access to care, at least as measured by having a usual source of primary care. The next question, however, is whether health insurance is enough.

Studies comparing the uninsured, Medicaid and private insurance status show that Medicaid-covered children are less likely to have an unmet need than uninsured. Having a medical home that provides an identified usual source of care as well as continuity of care was found to be essential in setting up programs for children.

Dr. Swigonski noted the same type of findings for CSHCN. Considering the prevalence of Medicaid managed care, **Dr. Swigonski** examined the Oregon Health Plan (OHP) to study the impact of Medicaid managed care for

CSHCN. Through a telephone survey, the study measured the outcomes of satisfaction and unmet needs of three populations of children: those enrolled in the Supplemental Security Income (who were generally more chronically ill and more severely affected); children with asthma; and children who were generally healthy in the OHP population.

The two hypotheses were that (1) if CSHCN had difficulty navigating complex organizational structures, then in Medicaid managed care there would be a decrease in satisfaction and an increase in unmet need; and (2) there would be a gradient effect of vulnerability with children who were more severely affected having the greatest difficulty in Medicaid managed care. The results showed no negative effect for CSHCN in Medicaid managed care relative to the general population. Access to specialty care, however, may be problematic for some children. There also was no gradient effect, which may be due to the planning and policies implemented for children with chronic conditions in Medicaid managed care programs, especially for the SSI population.

Studies are also underway looking at the State Children’s Health Initiative (SCHIP). The Children’s Health Insurance Research Initiative (CHIRI), funded through AHRQ, the David and Lucile Packard Foundation, and HRSA, involves nine studies of public health insurance and health care delivery systems that are being developed by the implementation of SCHIP. Seven of the studies are focusing specifically on children with special health care needs.

“Insurance is necessary but not sufficient to improve access and utilization for children. The structured organization of the health care system makes a difference, and we need policy and procedural safeguards for defining, identifying, and tracking children with special health care needs and for monitoring to ensure quality and services,” said **Dr. Swigonski**.

“Insurance is necessary but not sufficient to improve access and utilization for children. . . . We need policy and procedural safeguards for defining, identifying, and tracking children with special health care needs and for monitoring to ensure quality and services.”

- Dr. Nancy Swigonski

MODEL PROGRAMS

Kathy Higgins, Senior Director, Community Relations, Blue Cross and Blue Shield of North Carolina

Lowell Keppel, MD, Medical Director of Quality Improvement and Care Management, Blue Cross & Blue Shield United of Wisconsin

Roy Grant, Director, Referral Management Initiative, Division of Community Pediatrics, Children's Hospital at Montefiore, and Children's Health Fund

Be Active Kids

As a large health management company, Blue Cross and Blue Shield of North Carolina (BCBSNC) works collaboratively in the community to improve the health of its citizens.

Kathy Higgins explained a major initiative, **Be Active Kids**, from BCBSNC to promote physical activity and good nutrition to children with the goal of preventing injuries and disease. In partnership with the Governor's Council on Physical Fitness and Health, the Health and Fitness Foundation, the Cooperative Extension Service, and the North Carolina Nutrition Network, BCBSNC developed the Be Active Kids program to address serious health needs.

Research showed that in North Carolina, children were four times as likely to be obese as children nationally, were less flexible, had a greater percent body fat, and had poorer cardiovascular fitness. Many of those children had diets high in fat, low in fiber, and lacking fruits and vegetables. North Carolina also had the dubious distinction in 1996 of ranking 49th nationally in physical activity participation.

Be Active Kids is guided by four specific objectives: focus on nutrition and physical activity education for preschool children; train child care workers and Head Start teachers in use of the program; educate parents and caregivers to target physical activity and good nutrition, and implement a Be Active Kids program in child care and other centers serving limited resource children across the state.

The Be Active Kids vision is that every North Carolina preschool child will be physically active, healthy and ready to learn. The program provides a kit, which focuses on four- and five-year-olds, containing a curriculum notebook, visual aids, informational book on nutrition and physical activity, the Fun Family Ideas

newsletter, and flashcards. The interactive program integrates physical activity and nutrition into all aspects of the child's educational day, with lessons for math, science, music, drama, games and stories.

BCBSNC launched Be Active Kids in April 1999, and already 1,800 child care centers in 38 of North Carolina's 100 counties have implemented it. BCBSNC is committed to reaching all counties and is on track to do so sooner than its original 5-year goal. The program is being evaluated by the University of North Carolina School of Public Health.

"We believe that Be Active Kids will help children learn desirable dietary and physical activity habits early, hopefully to prevent the onslaught of diseases such as hypertension, diabetes, heart disease, and some cancers," said **Ms. Higgins**.

Collaborating on Quality of Care

Although many quality of care guidelines have been developed by various organizations in the health care system, successful implementation of them has been a challenge. Guidelines are a method of disseminating best practices for treatment of a disease as evidenced by scientific medicine; they also seek to minimize medical practice pattern variation. Guidelines are especially important for many of the chronic conditions that affect children, such as asthma and diabetes, noted **Dr. Lowell Keppel**.

Dr. Keppel described a collaborative effort by Blue Cross & Blue Shield United of Wisconsin along with six other managed care groups, five delivery systems, the Medical Society of Milwaukee, and the Milwaukee Health Department to develop a set of guidelines to improve the quality of care in Milwaukee. Based on concerns evident in a Medical Society of Milwaukee County-sponsored physician survey, the group overcame competitive pressures to address issues of health care quality affecting the local community. They set criteria for selecting the conditions to measure and the guidelines to pursue.

As the starting point, the group chose to

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- Kathy Higgins

address asthma and used the AHRQ asthma guideline as a model. Once developed, each participating organization endorsed the guideline and was responsible for measuring the outcomes individually. Since its introduction two years ago, the final guideline has received positive feedback from local physicians, media and accreditors. In addition, the guideline is listed in AHRQ's National Guideline Clearinghouse (www.guidelines.gov). The group also has other guidelines for diabetes.

Dr. Keppel emphasized that it is possible to bring competitors together to work collaboratively, particularly to improve health care quality. "I encourage you all to look for opportunities to collaborate in your own organizations with your competitors. When it's done well, everyone wins," said **Dr. Keppel**.

Referral Management Initiative

The Children's Health Fund, in partnership with Glaxo SmithKline, has implemented the **Referral Management Initiative (RMI)** in New York City to bring underserved children with chronic illness or at risk for chronic illness to specialty care providers as a way of improving their overall quality of care.

The Referral Management Initiative provides mail and telephone appointment reminders for specialist referral appointments, round-trip transportation to appointments, assistance navigating the health care system by meeting patients at the specialty site, facilitated communication between the specialist and the primary care provider, and coordination with health education to help families understand the need for the referral.

As **Roy Grant** explained, RMI assists a community with a high prevalence of chronic conditions and acute conditions that have progressed, many of which were not adequately managed and in some cases had never previously been diagnosed. Through RMI services, compliance with specialty appointments improved from under 10% to nearly 70%. Patient health education contributed to improved compliance.

Mr. Grant noted that many of the children

served by RMI are homeless, and the program provides care to this population through mobile medical units that bring the full pediatric clinic to homeless shelters and other places where these children can be reached. RMI serves the health care needs of medically underserved children, which can be severe, and their pediatric specialty care may be urgent. Neglect of their medical needs can also lead to serious and long-term financial consequences.

The RMI model itself has a cost. For health plans, though, tracking the outcomes of specialty appointments may help measure quality. "Whether it's a HEDIS measure, whether it's an internal continuous quality improvement measure, RMI might be a way for health insurance companies, to demonstrate the quality of what they do," said **Mr. Grant**.

Mr. Grant stressed that all of these children are Medicaid eligible, whether registered or not, but access is the key problem for them. Attempting to deal with the situation by increasing receipt of Medicaid will not relieve the real need for care.

Dennis Johnson with the Children's Health Fund added that one of the more promising aspects of having Medicaid patients in managed care is that medically underserved kids benefit from being in an organized system of care with the opportunity for oversight and case management. "There's a lot of promise with managed care, but we need to be ever mindful of the fact that whatever system of care underserved children are in, they need the extra support, [and] the extra ancillary services. . . . If there are barriers of access preventing them from keeping those specialty appointments, then the promise of having their care managed won't mean much," said **Mr. Johnson**.

NUTRITION AND CHRONIC ILLNESS

Sarah Barlow, MD, Assistant Professor of Pediatrics, St. Louis University School of Medicine

Katrina Holt, MPH, MS, RD, National Center for Education in Maternal and Child Health,

"I encourage you all to look for opportunities to collaborate in your own organizations with your competitors. When it's done well, everyone wins."

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- Roy Grant

Burton Edelstein, DDS, MPH, Chairman, Community Health, Columbia University School of Dental and Oral Surgery, and Director, Children's Health Project

"I think we can legitimately consider obesity at epidemic levels because of its rising prevalence and its associated with many health problems."

- Dr. Sarah Barlow

"Optimal nutrition can prevent health problems and reduce the risk of developing chronic disease."

- Katrina Holt

Obesity

As director of the Cardinal Glennan Children's Hospital weight management program, **Dr. Sarah Barlow** deals daily with the rising prevalence of childhood obesity. "I think we can legitimately consider obesity at epidemic levels because of its rising prevalence and its association with many health problems," said **Dr. Barlow**.

As the frequency of obesity in children and adolescents doubles and even triples, dealing with the disease is going to take innovative approaches to evaluation and intervention. Partnerships are crucial among private health plans, government, health care providers, and families.

The MCHB and NCEMCH convened a panel of experts to make recommendations for the evaluation and treatment of childhood obesity. These included identifying overweight children, assessing medical conditions for these children, and evaluating behavioral and emotional states.

To identify obese children, the panel promoted using the body mass index, with overweight being defined as greater than or equal to the 95th percentile body mass index. Evaluating medical conditions includes looking for conditions that cause obesity, immediate complications and associated conditions that increase long-term risks. Immediate complications of obesity include sleep apnea, Type II diabetes, orthopedic problems, hypertension, cholesterol and lipid disorders.

Understanding the family situation and its emotional view of the weight problem is critical prior to any intervention. Pushing families into trying to make changes without proper preparation can set the family up for failure. "There is not a magic cure for obesity ... It's a long-term problem that requires behavior change," said **Dr. Barlow**.

Dietary and physical activity assessments on all levels are necessary before changes can

be recommended. Diet assessment should include not only meals but the pattern of eating. All levels of physical activity should be examined prior to intervention, from vigorous activity such as gym and team sports, to unstructured activity such as recess and daily living activities.

In general, intervention should begin early. The foundation for change is through involvement of all family members and caregivers. Pediatricians, family care physicians, nurse practitioners, school nurses, and dietitians should all be engaged in treating the weight problem. Providers need support and assistance to improve care of obese children.

Dr. Barlow sees childhood obesity as an immediate and future health concern. It requires not only medical evaluation, but family-based intervention and community-wide support. She encouraged health plans to help develop guidelines for obesity. **Dr. Barlow** noted that for most overweight children, the health consequences are later in life.

General Approach to Obesity Therapy

- Intervention should start early
- The family must be ready for change
- Clinicians should educate families about medical complications of obesity
- Clinicians should involve the family and all caregivers in the treatment program
- Treatment programs should institute permanent changes, not short-term diets or exercise programs aimed at rapid weight loss
- As part of the treatment program, a family should learn to monitor eating and activity
- The treatment program should help the family make small, gradual changes
- Clinicians should encourage and empathize and not criticize
- A variety of experienced professionals can accomplish many aspects of a weight management program

* Source: Barlow, Sarah E. and William H. Dietz. Obesity Evaluation and Treatment: Expert Committee Recommendations. *Pediatrics*. September 1998.

Bright Futures and Nutrition

Katrina Holt introduced *Bright Futures in Practice: Nutrition*, the most recent Bright Futures guide, which provides screening tools, strategies, and resources for health professionals, families and communities on essential healthy eating and physical activity habits.

Bright Futures in Practice: Nutrition builds on the Bright Futures guidelines for health supervision and health promotion for infants, children and adolescents. The guide integrates nutrition as part of broader health services. “Optimal nutrition can prevent health problems and reduce the risk of developing chronic disease,” said **Ms. Holt**.

The Bright Futures project builds partnerships in promoting good nutrition through sharing information as well as resources, and also through educating health professionals, individuals working in community programs and families. The *Bright Futures in Practice: Nutrition* guide was developed for a wide array of health professionals (physicians, dietitians, nurses, child care providers, program administrators) and families.

Bright Futures in Practice: Nutrition continues the developmental and contextual approach within Bright Futures to help children and adolescents develop positive attitudes toward food and practice healthy eating behaviors. The developmental approach is based on the unique social and psychological characteristics of each of the developmental periods, and the contextual approach emphasizes the promotion of consistent nutrition messages.

The general health supervision visit can be used to implement nutrition programs for standards of practice and protocol and also to train and educate professionals. In the community, the guide can serve as a resource for program staff and to develop education materials. Information provided also can be used to enhance policy and practice. **Ms. Holt** also noted that the nutrition guidelines can be incorporated into a health plan guideline to enhance nutrition screening, assessment and counseling.

Bright Futures in Practice: Nutrition has been used widely in education and training, particularly for health professionals. The US Department of Agriculture’s supplemental food program distributed the guide to all state and local programs to train their staff. The guide has also helped universities develop materials and local governments enhance their nutrition services.

NCMCH currently is working on other materials based on the nutrition guide, including a factsheet for families and a pocket guide for health professionals. The guide and additional information are at www.brightfutures.org.

Most Common Chronic Condition

Labeling the medical delivery and financing systems as a placental system, and the dental delivery and financing systems as a marsupial system, **Dr. Burt Edelstein** noted that “you can’t get this placental system and this marsupial system to come together to produce any kind of a reasonable offspring. They’re just two completely different systems...with a significant integration problem.”

Yet dental caries is a chronic illness and the most prevalent disease of childhood. While dental disease is infectious and transmitted to infants by their mothers before age two, the American Academy of Pediatrics recommends the first dental visit at age three, creating a disconnect in dealing with the condition. Dental organizations, the American Public Health Association, and Bright Futures all recommend that a child’s first dental visit be at age one. Hence, it is necessary to turn to the medical system, which treats children regularly in the first two years, to address these issues.

As **Dr. Edelstein** noted, children whose capacity to eat, sleep, play and learn is compromised because severe dental disease forms an unrecognized group of children with special health care needs. For four to five million children, the disease is so severe that they fail to thrive nutritionally, medically and behaviorally. Dental caries are five times more prevalent than asthma. In addition, a variety of dental, oral and craniofacial conditions constitute chronic threats to the general health

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- Dr. Burt Edelstein

and well being of all children. All of the conditions that establish adult periodontal disease occur in childhood.

Oral health presents a special challenge to children with chronic and debilitating conditions and is often overlooked by parents and providers. Oral and dental problems can aggravate many conditions, such as diabetes, asthma, cardiac disease, and eating disorders.

Children with special health care needs who are uninsured experience an extreme level of unmet need for dental care that is three times more common than medical, four times more common than vision, and five times more common than unmet prescription needs. For CSHCN, nearly one in four are reported by their parents to have an unmet dental need.

Dental health is sentinel for a variety of child health issues important to providers, payers and patients. “Whether you’re looking at unmet need or coverage or enrollment or access or disparities or the safety net, no matter where you look, you’re going to find that ... if you want a worst case health issue for the kids, it’s oral

health,” said **Dr. Edelstein**.

Dr. Edelstein encouraged everyone to integrate dental health into overall childrens’ health and observed that oral health as an overall health issue is finally getting serious attention. Numerous public agencies and private organizations are working on oral health initiatives. Pediatricians can be trained to identify higher risk children and use the traditional approach of pediatrics, risk assessment, anticipatory guidance, primary prevention and disease suppression.

Dr. Edelstein suggested that the medical care system work to identify those kids in need of dental care and link them to the dental delivery system, thereby negating the essential problems between the two systems.

The *Bright Futures in Practice: Oral Health* guide provides anticipatory guidance on oral health, some of which was integrated into the nutrition guide. For additional information on oral health as a public health problem, visit the National Oral Health Resource Center’s website at [www.ncemch.org/oral health](http://www.ncemch.org/oral%20health).



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A PUBLICATION OF THE NIHCM FOUNDATION

About The NIHCM Foundation

The National Institute for Health Care Management Research and Educational Foundation is a non-profit organization whose mission is to promote improvement in health care access, management and quality.

About This Action Brief

This Brief was written with support from the Health Resources and Services Administration’s Maternal and Child Health Bureau, Public Health Service, U.S. Department of Health and Human Services, under cooperative agreement No. 5 U93 MC 00143-03. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the Maternal and Child Health Bureau. Therese Finan, NIHCM Foundation, prepared the Brief.