DISABILITIES

PHOTOCOPY
PRESERVATION

DISABILITIES

PHOTOCOPY
PRESERVATION

Jill

Melanne — here is the response to the guy in Maine

Pam

THE WHITE HOUSE
WASHINGTON

March 26, 1994

Mr. David Allen
Penobscot Valley Industries
611 Hammond Street
Bangor, Maine 04401

Dear Mr. Allen:

Thank you for writing about the needs of people with disabilities. I remember speaking with you at the University of Maine and am writing to provide additional information about how health care reform will help people with disabilities.

For too long, people with disabilities have faced discrimination in the health insurance marketplace. Many are prevented from purchasing insurance because they have a so-called "pre-existing condition". Those able to obtain insurance are often forced to pay the highest rates. And many reach lifetime limits on benefits just when they need coverage the most.

The President's health care reform proposal will guarantee private insurance coverage to every American that can never be taken away. In addition, the proposal outlaws unfair insurance practices. It will be illegal for insurance companies to drop coverage or cut benefits, increase your rates if you get sick, use lifetime limits to cut off your benefits, and charge higher premiums based on health condition or age.

The comprehensive benefit package that will be available to every American includes health professional and hospital services, clinical preventive services, mental illness and substance abuse services, home health care, extended care, rehabilitation services, durable medical equipment and many other services that are essential to people with disabilities. You asked specifically about treatment for mental illness under the health care reform proposal. The mental illness and substance abuse benefit emphasizes a wide range of innovative treatment options, including case management, partial hospitalization, day treatment programs, and home-based and behavioral aide services.

In addition to the services in the comprehensive benefit package, the President's proposal expands long-term care services for people with severe disabilities, regardless of age or income. This new program will provide home and community based supports

for up to 3.1 million people. People who receive Medicaid and live in nursing facilities or intermediate care facilities for the mentally retarded will be permitted to keep more of their monthly income for personal expenses. The long-term care program also helps people with disabilities who work by authorizing a 50 percent tax credit, up to $15,000 each year, for work-related personal assistance and other services.

Thank you again for writing. I very much appreciated hearing your thoughts and concerns about health care reform.

Sincerely yours,

Hillary Rodham Clinton

Hillary Rodham Clinton

cc: Senator George J. Mitchell

No. 651

ISSUE BRIEF

NATIONAL HEALTH POLICY FORUM

Meeting the Needs of Chronically Disabled Children in a Changing Health Care System

Thursday, July 14, 1994
1:30 to 4:30 pm
Quality Hotel Capitol Hill
Federal Ballroom

A roundtable discussion featuring

Jack Shonkoff, M.D.
Dean
Florence Heller Graduate School for Advanced Studies in Social Welfare
Brandeis University

Margaret McManus
President
McManus Health Policy, Inc.

David Corro
Chief Executive Officer
Health Services for Children with Special Needs, Inc.

Mandy Sweeney
Director of Eligibility Programs
Medicaid Bureau
Division of Medical Assistance
Massachusetts Office of Health and Human Services

with comments by

Eva Skubel
Coordinator
Health Financing Advocacy Project
The Family Center
Newington Children's Hospital

Merle McPherson, M.D.
Director
Services for Children with Special Needs Division
Maternal and Child Health Bureau
Department of Health and Human Services

Registration: Please call **Dagny Canard at 202/872-1392** as soon as possible.

The George Washington University
WASHINGTON DC

Meeting the Needs of Chronically Disabled Children in a Changing Health Care System

Managed care is fast becoming the dominant health care delivery model in America. But how well this cost-containing approach responds to the needs of some four million chronically disabled children who require more care than their healthier peers is of major concern.

Managed care, whether in the form of a health maintenance organization (HMO) or more loosely constructed hybrids, such as independent practice associations (IPAs), preferred provider organizations (PPOs), or point of service (POS) plans, all theoretically share the traits of coordinating care for patients, stressing primary care, and conducting utilization review to curtail delivery of unnecessary care.

While the low cost-sharing requirements and care coordination offered by these plans are clear advantages, many caution that the cost-limiting incentives that drive managed care are fundamentally in conflict with disabled children's health care needs. Financial incentives to restrict services can threaten their access to specialists and an array of necessary therapies. Moreover, children who are granted specialist referrals may find that plans do not contract with specialists in childhood disorders and instead send them to providers who lack pediatric expertise.

These problems are not insignificant. Medical experts note that childhood conditions treated inadequately can destroy children's potential for lifetime normal functioning or compromise their adjustment to a disability.

Nonetheless, these potential conflicts are not deterring the flow of chronically disabled children into managed care plans. In 1989, with the number of chronically disabled children standing at 3.4 million, some 680,000, or 20 percent, were enrolled in either HMOs or IPAs. This figure was up from 13 percent in 1986—and Congress may pass health care reform legislation that would accelerate this trend. These numbers may stimulate policymakers to address just how good a fit managed care is for serving chronically disabled children. In considering this issue, a range of questions arise, including how the model might be improved to ensure access to appropriate services and providers, whether all services should be provided within one plan or certain services brokered through outside specialty managed care or fee-for-service plans, and whether disabled children belong in managed care at all.

Two financial concerns are central to the question of whether managed care plans can serve people with disabilities well. One is how plans can set reasonable capitation rates to reflect this group's burden of illness while maintaining competitive premiums. The other is how to encourage more equitable distribution of this high-cost population among health plans through risk adjustors or other mechanisms.

While ensuring a responsive delivery system is crucial for chronically disabled children, adequate benefits coverage is also a concern. The current picture of insurance coverage for families with disabled children is mixed, with some receiving generous benefits while others pay out of pocket for needed services (for example, physical, speech, and other therapies and home care). Parents' liability for medical expenses could well increase if a health care reform bill sets a standard benefits package that omits many of the services these children need. Whether through health care reform or market trends that make more liberal fee-for-service plans scarce, the issue of how much cost these families should reasonably be expected to shoulder will escalate. The use of public means to fund out-of-plan services may arise as an equity issue at the state and federal levels.

At this Forum session, speakers will discuss the varying needs of this special population and how well

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the commercial market is meeting them. They will also explore effective managed care delivery models for providing appropriate services as well as options for financing current and potential coverage gaps.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Nearly one-third—about 20 million—of all children in the United States have one or more chronic physical, developmental, learning, emotional, or behavioral problems. The five most common chronic physical conditions are respiratory allergies, frequent or repeated ear infections, asthma, eczema and skin allergies, and speech defects. Most children are mildly affected by their conditions.

However, for a small but growing segment—four million, or nearly 20 percent, of all children with chronic conditions—their disabilities interfere with normal childhood activities such as school and play, according to analyses of the 1992 National Health Interview Survey (NHIS) conducted by researcher Paul Newacheck at the University of California, San Francisco. The most frequently reported causes of disability for these children are mental and nervous system disorders, such as mental retardation, neurotic and personality disorders, epilepsy, and cerebral palsy. The second leading cause is respiratory system diseases, principally asthma, followed by orthopedic impairments and deformities.

Children with chronically disabling conditions are disproportionately poor, adolescent, and male. Children below the poverty line are 60 percent more likely to be disabled than those living above it; adolescents are three times as likely as preschool-aged children to suffer disability (many chronic conditions worsen during adolescence); and boys are 50 percent more likely than girls to have an activity limitation.

Children with chronically disabling conditions range from those who attend regular schools but cannot play sports to those who must attend special schools to those who cannot attend school at all. Of these four million children, Newacheck's data show a small portion—396,000—so severely disabled that they cannot attend school or, for the preschool-aged, engage in ordinary play. An additional 40,000 live in long-term care institutions.

A much larger subset of the four million—almost three million children—can be classified as mildly or moderately disabled. These children face limits in the amount or nature of play and school activities in which they can engage. They often require special schools or special teachers or cannot attend school full-time.

Children with mild, moderate, and severe disabilities commonly need care beyond typical hospital, physician, and prescription drug services. These may include occupational and physical therapy, home care, speech-language pathology, and psychosocial support services. And a recent study by Newacheck found that up to two million children may require long-term home- and community-based services. This estimate is based on the number of children who meet the disability criteria of the Supplemental Security Income (SSI) program.

Since 1960, the proportion of children with disabilities has more than tripled, now standing at almost 6 percent of all children. Medical advances over the past few decades are believed to have fueled this increase. For example, since the 1960s, sophisticated neonatal intensive care technology has kept more low-birthweight babies alive. In 1960, according to the National Center for Health Statistics, only 28 percent of low-birthweight babies lived past their first birthday. Today more than half do, but their survival may be a mixed blessing. Due to underdeveloped respiratory and neurological systems, many require high-tech care, such as ventilators and tracheotomy tubes, in their early months or throughout their lives. These babies are at high risk for a variety of chronic, handicapping conditions such as respiratory problems, blindness, deafness, and mental retardation.

Children with chronically disabling conditions are also living longer due to advances in medical care. In 1940, for instance, children with cystic fibrosis were expected to live only until age two; in 1990 their average life expectancy was 28 years.

A great deal has been written about children with chronic physical problems. Far less is known about children with developmental, learning, behavioral, and emotional problems, despite their prevalence in our society. National data compiled in 1988 by researcher Nicholas Zill and his colleagues found that as many as 20 percent of American children have had one or more developmental delays, learning disabilities, or emotional or behavioral problems. These include about 4 percent (2.5 million) of children under 17 who have experienced either temporary or longstanding growth or developmental delays and almost 7 percent (3.4 million) who have learning disabilities. The research also found that about 13 percent of children had experienced emotional or behavioral problems, the most common of which are attention-

deficit disorder, phobias and anxiety disorders, and childhood depression. Children with special health care needs cannot be neatly labeled as having either physical, emotional, learning, or behavioral problems, since the co-occurrence of conditions in this population is so strong.

Case Examples

Lisa is a 12-year-old with scoliosis, a curvature of the spine. About twice a year, she needs access to a pediatric orthopedist who is aware of how the disease manifests itself in children, and once a week she requires physical therapy sessions to limit progression of the curvature. Lisa also needs to see an orthotic specialist who can fit her for a soft spinal jacket to prevent further spine curvature. Without these services she would likely require complex surgery to have rods implanted in her back. Finally, Lisa is in need of counseling to deal with her depression and low self-esteem brought on by the circumstance of entering adolescence with an orthopedic deformity.

Jacinta is a 12-year-old who has suffered since birth from the most severe form of Lissencephaly, a brain disease in which the cerebral cortex is not normally developed. Jacinta is blind, unable to talk or walk, and suffers from severe seizures and poor swallowing. She currently has 12-hour nursing care in her home and requires a range of medical equipment, such as feeding tubes, a suction machine, a ventilator at night when there is no nurse to monitor her, an oximeter to check the oxygen levels in her blood, and leg braces.

Michael is an eight-year-old with severe asthma. He has monthly episodes triggered by any number of factors—stress, strenuous exercise, or an allergin —during which he experiences extreme shortness of breath and intense wheezing. Michael takes prednisone (a bronchodilator) routinely, but sometimes he or his mother does not detect the onset of a serious attack soon enough; about six times a year his asthmatic episodes are so severe that he is taken to the hospital emergency room, stabilized, and kept for three to four days for monitoring.

Johnny, a playful four-year-old, has been found by his preschool teacher to be showing some signs of developmental delay: a preference for nonverbal play, inability to follow instructions appropriately, and difficulty in choosing the right words to express himself. A developmental psychologist has determined that his problems are related to deficits in auditory processing. Both the psychologist and Johnny's pediatrician believe that his condition is not solely neurologically based but may be caused by hearing loss due to persistent ear infections since birth. After being sent to an audiologist for further testing, Johnny is seeing a speech-language pathologist specializing in developmental delay. She will be providing weekly therapy for an undetermined period to improve his listening and language skills.

Service Utilization and Costs

Not surprisingly, children with chronically disabling conditions consume considerably higher amounts of health care than other children. According to the 1980 National Medical Care Utilization and Expenditure Survey (NMCUES), these children were twice as likely to be hospitalized during the course of a year and their average length of stay was four times longer than that of other children. They made almost twice as many physician visits and five times as many visits to nonphysicians (for example, ancillary therapists and psychologists); received twice the number of medications; and required twice the amount of medical equipment as other children. Children with disabilities incurred health care expenses three times as high as other children, averaging almost $2,000 per disabled child in 1992 dollars.

Among children with disabilities, only a small portion consume the lion's share of expenses for the entire cohort. The most recent data available show that in 1980 10 percent of children with disabilities accounted for 65 percent of all costs incurred by this group, according to researchers Newacheck and Margaret McManus.

CHRONICALLY ILL CHILDREN AND THE COMMERCIAL INSURANCE MARKET

Benefits

There is no doubt that Medicaid is the most generous health care plan for chronically disabled children. The 24 percent (over 800,000) of such children who are insured by Medicaid have access to a range of ancillary therapies, home care, mental health, case management, and transportation to medical services without any arbitrary cap on number of annual visits or lifetime medical expenditures. Under Medicaid's Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, they also enjoy extended coverage for virtually all Medicaid benefits.

National data from 1989 offer the most current figures on the portion of chronically disabled children with private insurance—about 62 percent, or roughly two million. About 32 percent, or approximately 680,000, of them were enrolled in HMOs. No data are available on how these children currently fare in the commercial market, but earlier surveys suggest that, while coverage is generous for a sizeable portion, many face restrictions and duration caps on ancillary therapies and home care, and some are not covered for these services at all.

In 1987 researchers Newacheck and Harriette Fox surveyed 150 small, medium, and large employers to get a picture of benefits provided under traditional indemnity or PPO plans. Their major findings include the following: More than 90 percent of plans provided coverage for medical supplies, medical equipment, x-ray and lab services, and prescriptions. A majority of plans covered physical therapy (87 percent), and speech therapy (77 percent), while relatively fewer (57 percent) covered occupational therapy. However, insurers commonly required these therapies to be used to restore lost functioning associated with an illness or injury. These restrictions limit coverage for children who need to improve their age-appropriate function and for those who have congenital problems.

Nearly 70 percent of plans provided comprehensive home care, defined as including occupational, speech, physical, and respiratory therapies; social work; skilled nursing; and home health aide services. But more than three-quarters of the plans restricted the number of home care visits to 90 annually.

On the issue of patient cost liability, nearly three-quarters of all plans set their lifetime benefit levels at $1 million. Half of the plans set annual out-of-pocket limits between $1,000 and $2,000; one-quarter of them set limits below $1,000; and the rest either set them above $2,000 or had no limits at all.

HMOs have also placed significant restrictions on the benefits they provide to this population, according to a 1989 survey of 59 HMOs by Fox Health Policy Consultants. Benefits for medical equipment, medical supplies, and prescription drugs were less prevalent among HMOs than among traditional plans. And, while HMOs were somewhat more likely to cover ancillary therapies, 90 percent of those surveyed explicitly limited either the number of consecutive days or the number of visits allowed for these therapies, most often to 60. The survey also found that while nearly all the HMOs surveyed offered home health benefits, they were commonly offered only when they could serve in lieu of more costly care in a skilled nursing facility or hospital or when the patient's condition was expected to improve within 60 days. Most importantly, the survey found access to ancillary therapies and home health care frequently to be limited to children with acute conditions, those expected to recover quickly, or those needing to restore lost function. These plans generally excluded children who needed ongoing therapies and care to maintain their limited functional capacity.

COPING WITH COVERAGE GAPS

In view of the widespread coverage restrictions in commercial plans, many families either pay out of pocket for additional services or seek help from Title V programs, school early intervention and special education services, and voluntary associations. Children meeting Medicaid's categorical requirements are in much better shape in terms of access to a comprehensive benefits plan.

The groups that frequently end up having to pay substantially for services are uninsured families and middle-income families with mildly and moderately disabled children, according to researcher McManus. The latter group seldom qualifies for Medicaid or Title V programs, yet the ongoing services they need are very costly. For example, a low-birthweight baby is sent home after one month in the hospital, and her insurance company pays for three months of comprehensive home care because it is in lieu of hospitalization. After three months, the family has exhausted its home care benefit and the parents are on their own to manage the child's care at home, including dealing with respirators, feeding tubes, and other needs.

Title V agencies often provide services for underinsured children in areas such as home care, ancillary therapies, and medical equipment. The range and generosity of benefits varies by state and is determined in part by agency budgets and how much gap-filling of private coverage is needed. But Title V's reliability as a supplemental funding source rests tenuously on state and federal appropriations, and it is unclear how budgets for public health programs will fare under health systems reform or in the next round of federal appropriations. Federal Title V funding for direct care may in fact be cut to help pay for the cost of health care reform. At the same time, it is not at all certain that private insurers would be required to fill in the coverage holes that Title V now fills.

Public schools are also required by federal law to be the payers of last resort for services that support

the learning of children in special education. While these can be health-related services, including ancillary therapies and assistive technologies, the condition of coverage is to further the educational goals, not the health needs, of the child. Numerous battles have been waged between schools and insurers over whether services are medically or educationally necessary. Currently, no clear policies exist over which party should pay when services can fall into either category, and there is little evidence of coordination between schools and insurers in distributing responsibility for coverage.

The real losers, note many experts, are children with developmental, behavioral, and neurological impairments whose service needs are not well-defined and are often dismissed as not medically necessary by insurers. According to Eva Skubel, who assists families of chronically ill children in Connecticut with insurance issues, payers often deny coverage for physical and speech therapy for children with developmental delays, claiming that, while the therapies are perhaps educationally appropriate, they are not medically necessary.

Disputes over when services are medically necessary, the most common problem Skubel confronts, are not restricted to cases involving developmental delays. For example, she says that insurers she has dealt with frequently terminate skilled nursing home care between eight and twelve weeks, claiming it is no longer medically necessary but custodial, even though a child's condition or diagnosis has not changed.

Currently, families who legally challenge insurers' judgements of medical necessity are not meeting with much success, according to attorneys Elizabeth Jameson and Elizabeth Wehr. In a 1993 article on chronically ill children, published in the *Stanford Law and Policy Review*, they note that the legal function of the medical necessity clause is to limit a plan's obligations to its beneficiaries and that contract doctrine supports a plan's authority to interpret the phrase broadly. "Two decades ago, the judgement of a child's treating physician that a health service would be helpful sufficed to establish its necessity both for plans and courts reviewing any dispute. Current standard practice, however, is for plans to reserve to themselves the discretion to make these judgements and courts to uphold them."

CHRONICALLY DISABLED CHILDREN AND MANAGED CARE

In addition to the privately insured, a small but unknown portion of chronically disabled children on Medicaid are enrolled in HMOs. In 1993, 36 state Medicaid agencies were offering a managed care option, according to the General Accounting Office, and a handful were mandating it. But of those states mandating HMO enrollment, most exempt certain groups of special needs children—commonly SSI, Title V Children with Special Health Care Needs, and foster care children.

Overall, researchers have noted several advantages HMOs offer families of disabled children over fee-for-service plans. Nearly all HMOs offer coverage for well-child care and routine immunizations, while traditional indemnity plans are much less likely to. Moreover, HMOs are far more likely to protect families against excessive medical costs; many have no cost-sharing requirements for covered benefits, and most HMOs offer unlimited lifetime benefits.

The HMO design also holds much promise for solving the care coordination problems that many chronically disabled children face, say researchers. Well-trained primary care gatekeepers can provide for the routine care these children often miss; they can also coordinate the use of various therapies and specialty referrals, as well as promote dialogue among providers.

However, the experience of HMOs in meeting the unique needs of chronically disabled children has been mixed. Parent advocates note that, while some families are satisfied with their managed care arrangements, a number of trends in HMO practice have been found to work against the health needs of chronically disabled children. Two of the most common problems these children face in managed care are insufficient access to needed services, particularly pediatric subspecialty providers, and inadequate pairing with primary care gatekeepers trained to detect the unique problems of this population and provide appropriate routine care.

Access to Services

One of the purported strengths of managed care is its built-in financial incentive for primary care providers, acting as gatekeepers to services, to avoid the use of costly and unnecessary diagnostic services and specialty care. Under capitated payment arrangements, annual plan budgets are set and incentives to reduce service use are increased greatly. Experts caution that the financial incentives to ration care often translate into the denial of necessary services for many children. This is especially critical because treatment protocols for many chronic conditions are poorly defined—particularly for developmental, behavioral, and emotional problems—giving families little ammunition to argue that certain services are medically necessary.

Historically, providers in fee-for-service plans have often gamed the codes to get insurers to pay for extended therapies or referrals. In managed care, financial disincentives work against this provider-as-advocate role.

Financial incentives to ration care also are believed to contribute to referral denials for pediatric specialists, such as pediatric cardiologists and allergists, in managed care arrangements. A 1989 evaluation of the Medicaid Competition Demonstrations—Medicaid managed care experiments conducted in the early 1980s—found the proportion of children seen by a specialist declined an average of 53 percent after enrollment in managed care. Although inappropriate referrals may have been occurring before enrollment, the size of this reduction has concerned researchers.

Even when children gain specialty referrals, in many cases plans fail to contract with a range of pediatric subspecialists and instead require that chronically disabled children use in-plan adult specialists. Experts claim this leaves the door open for complex or rare problems to go undiagnosed and untreated due to a lack of expertise. Jameson and Wehr cite one survey of referring providers in HMOs and PPOs that found a substantial portion of doctors complaining that denials for pediatric subspecialists threatened health outcomes. These providers predicted problems ranging from continued ear infections to delayed cancer diagnoses to lack of intervention for anorexia, bulimia, and child abuse.

Primary Care Gatekeepers

Anecdotal accounts from both researchers and parents indicate a lack of expertise among primary care gatekeepers in serving certain chronically disabled children. There has been some criticism that primary care providers feel uncomfortable at times giving even routine care to children with complex conditions. This poses problems for many children and families who have terminated longstanding relationships with previous providers to enter managed care. To address this concern, some plans are experimenting with using specialists as primary care providers for certain children.

HEALTH REFORM PROPOSALS AND CHRONICALLY DISABLED CHILDREN

One of the critical issues before Congress under health care reform is the setting of a benefits package. In this arena, pressures to create a modest, cost-containing package are competing with consumers' desires to preserve the generous benefits that many now enjoy. Even though a modest standard benefits package would not preclude more generous coverage, insurance experts confirm that in an environment driven by competitive bidding, most employers and health plans would have little incentive to offer more than the standard package.

For this reason, both the acute-care benefit package and long-term care provisions of the administration's Health Security Act (HSA)—the springboard for congressional negotiations—did not receive cheers from the children's disability community. In the bill, outpatient rehabilitation services (occupational, physical, and speech therapies) would be available only to restore functional capacity or minimize limitations following an illness or injury. This would exclude coverage for children with congenital and developmental conditions and for those who require therapies to improve age-appropriate functioning. Absent from the bill are full-time home nursing care, respiratory therapy, audiology services and hearing aids, and psychosocial support services, for which many children are currently covered. In addition, eligibility for the bill's long-term care benefits, which would provide personal care assistance and possibly other services, would be restricted to only a small portion (fewer than 100,000) of the most severely disabled children, and no caps would exist on out-of-pocket liability for services.

Since the HSA's introduction, various congressional committees have warmed to the idea of broadening coverage for chronically disabled children. If a health reform bill comprehensive enough to dictate a benefits package is passed, there are strong indications of support in both House and Senate for at least extending outpatient therapies to children with congenital and chronic conditions. In addition, a number of committees, including House Ways and Means and Senate Labor and Human Resources, have added other benefits, such as hearing aids, for children.

However, given the fluidity of health care compromise as well as Congress's desire to limit the cost of health reform for the government and employers, it is nearly impossible to predict whether changes in the standard benefits package or children's long-term care provisions will be adopted. With the White House softening on its earlier commitment to immediate universal coverage and with growing congressional opposition to employer mandates, the prospects for any long-term care benefits package, much less a

children's add-on, now appear dim. Nevertheless, there are key lawmakers who support such coverage.

Attached to the long-term care section of the bill recently passed by the Senate Labor and Human Resources Committee was a new children's benefits package that would provide Medicaid's generous EPSDT benefits to children with severe activity limitations. This program would be financed with a 2 percent set-aside in the long-term care budget. And, at this writing, the Senate Finance Committee is giving thought to providing more generous benefits to children by increasing states' Medicaid match rates, although a specific proposal has not yet been crafted.

Even a minimalist approach to health systems reform would be beneficial to this population. More incremental proposals aimed at reforming the insurance industry would ban any preexisting conditions exclusions and require plans to renew members who are sick.

QUESTIONS FOR DISCUSSION

Regardless of the extent of congressional action on health care reform, managed care is fast becoming the dominant form of health delivery in the commercial market, and issues surrounding the treatment of chronically disabled children in managed care systems remain. Debates over the proliferation of managed care should explore how this system can be tailored to meet the needs of chronically disabled children or whether these children belong in the system at all.

Moreover, liability for medical costs may increasingly fall on families of chronically disabled children as fewer employers offer fee-for-service options. This trend raises questions about the appropriate balance between the costs these families should reasonably be expected to shoulder and federal and state governments' responsibility in paying for care.

Other questions for consideration include the following:

- Should chronically disabled children be mainstreamed into managed care plans, served by specialty managed care systems, or served exclusively in preferred provider systems?
- How can managed care plans set appropriate capitation rates to reflect chronically disabled children's burden of illness?
- Should chronically disabled children be allowed to continue ongoing relationships with out-of-plan providers upon entering managed care systems?
- Should pediatric subspecialists be made the primary care gatekeepers for certain chronically disabled children? What, if any, provisions should be made to train primary care gatekeepers about the unique needs of chronically disabled children?
- Should all managed care plans be required to contract with a range of pediatric subspecialists and hospitals specializing in the care of children? If not, what mechanisms are in order to ensure access to appropriate providers when none exist within plans?
- What quality-of-care mechanisms should be pursued to assure that plans offer high-quality care to children with a range of disabling conditions, many of them rare?
- What protocols, if any, should be constructed to review whether managed care plans should cover new medications, therapies, or interventions to improve the prognosis of these children? Should plans, or another entity, be allowed to make these decisions?
- What safeguards should be in place to ensure that utilization review committees have some expertise in the various needs of children with chronically disabling conditions?
- Who, if anyone, should be responsible for the development of practice guidelines for children with developmental, behavioral, and emotional conditions that are now ill-defined?
- How will managed care plans coordinate care with other systems that serve these children, such as the schools, Title V, and mental health systems?

THE FORUM SESSION

Jack Shonkoff, M.D., will begin the session with an overview of the range in severity of conditions affecting chronically disabled children and of their varying service needs. Dr. Shonkoff is the new dean of the Florence Heller Graduate School for Advanced Studies in Social Welfare at Brandeis University. Formerly a fellow in developmental pediatrics at Harvard Medical School and the Children's Hospital Medical Center in Boston, he specializes in the study of atypical development in young children. Dr. Shonkoff has served on numerous organizational and editorial boards and for the past ten years has been the principal investigator and project director of the Early Intervention Collaborative Study, a longitudinal

investigation of the development of biologically vulnerable infants and their families.

Margaret McManus will follow with a discussion of how chronically disabled children are faring in managed care systems. She will also describe coverage gaps and families' liability for services in the commercial market. Ms. McManus, president of McManus Health Policy, Inc., a Washington-based consulting firm, is a health policy researcher who focuses on the financing and delivery of health care for children and adolescents. She has worked with numerous federal and state government agencies and is also co-director of the Maternal and Child Health Policy Research Center, where she is involved with studies concerning the impact of health care reform on children, Medicaid managed care, prevalence and impact of chronic conditions, and more. She has also been a consultant for the American Academy of Pediatrics' Child Health Financing Committee for the last ten years.

Speaking on innovative managed care delivery models will be **David Corro**, chief executive officer and founder of Health Services for Children with Special Needs (HSCSN), Inc., in Washington, D.C. Through the D.C. Medicaid agency, HSCSN has applied for a federal 1115 demonstration waiver to serve the District's population of chronically disabled Medicaid children in a specialty managed care system. The system would use practice guidelines and performance standards to improve the quality of care for some 3,600 disabled children, as well as establish a centralized information system to judge health outcomes and set capitation rates. Prior to founding HSCSN, Mr. Corro was chief financial officer and administrator for the Hospital for Sick Children in Washington.

Turning to options for financing uncovered services for chronically disabled children, **Mandy Sweeney**, director of eligibility programs for the Massachusetts Medicaid Bureau, will describe CommonHealth, the state's health insurance program serving disabled children and working adults. Since 1988 CommonHealth has been a state-funded Medicaid buy-in program offering the EPSDT benefit package on a sliding-fee scale to disabled children whose families' incomes exceed Medicaid's eligibility criteria. In 1993 the program served 1,450 children. Ms. Sweeney has held various management positions within Massachusetts Medicaid since 1987 and has been involved in the development and management of the CommonHealth program since its inception.

Other experts will be on hand to provide perspectives on parents' difficulties in accessing and getting coverage for services as well as the role of Title V in serving this population.

Eva Skubel is coordinator of the Health Financing Advocacy Project in the Family Center at Newington Children's Hospital in Connecticut. There, she assists hundreds of families in securing resources to pay for services for their chronically disabled children. Ms. Skubel is also the mother of a medically complex child, is a legislative and policy consultant to various state agencies, and has testified numerous times before the members of the Connecticut legislature as well as the U.S. Senate on issues concerning care and insurance coverage for this population.

Merle McPherson, M.D., is director of the Maternal and Child Health (MCH) Bureau's Services for Children with Special Needs Division within DHHS. Dr. McPherson is a fellow of the American Board of Preventive Medicine and of the American Board of Pediatrics. She has administered the Title V Crippled Children's program in D.C. and the Tile V Maternal and Child Health and Family Health Services programs in Hawaii. Since 1976, Dr. McPherson has held various positions in the federal MCH bureau.