Challenges for Decisionmakers: How Managed Competition Could Affect Children with Special Health Care Needs

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EXECUTIVE SUMMARY

This briefing report is written to alert public and private sector decision makers to the potential advantages and disadvantages of a health care reform strategy based on managed competition from the perspective of an important and vulnerable population—children with special health care needs. Nearly a third of all children in the U.S. currently have a chronic physical, developmental, learning, emotional, and behavioral problem. A small but growing proportion of children -- 6 percent nationwide—are limited in their ability to play or to attend school. Many of these children are poor; in fact, poor children are more likely to experience severe health problems than their nonpoor counterparts.

The United States stands poised to legislate and implement health care reform on a national level, even as reforms are being implemented in states and localities. A substantial amount of activity has coalesced around reform based on two related approaches: managed competition and managed care. Managed care is an approach to delivering health care that is featured prominently in a managed competition model, but it is rapidly developing on its own and will play a large part in the future regardless of the specific reforms enacted.

Several features of the managed competition model hold the potential to help children with health problems, including:

- Incentives for consumers to enroll in health plans that emphasize coordination of services and continuity of care;
- Insurance reforms that would limit insurers' ability to exclude high-risk patients, restrict their coverage, or charge exorbitant rates based on health status;
- The opportunity to choose from a wider variety of health plans and enroll in one that meets an individual's specific needs;
- An emphasis on measuring quality and provider performance and making this information available to the public.

A managed competition model, however, also holds some potential for harm for children with special health needs. Some of these negative "side-effects" are built into the incentive structure inherent in the model. Some arise if the model is implemented inappropriately. And others are common to any health reform plan that tries to hold down the growth of health care spending. This report signals a warning bell by highlighting these negative side-effects.
Policy Issues

Five elements of managed competition are featured in the report and warrant special attention from policymakers.

- **Elimination of Medicaid**: Some managed competition proposals would mainstream the Medicaid population into purchasing cooperatives or alliances. This would remove the stigma of a welfare program from the process of receiving health care, and it could broaden access to primary care physicians. But eliminating Medicaid could also create some new difficulties for a population that may require significant non-medical services that have been provided through Medicaid. This could be especially problematic because a disproportionate number of children with disabling chronic conditions are part of the Medicaid program.

Another critical issue concerns the type and extent of subsidies provided by the government. Under many proposals, the poor and near-poor would receive subsidy amounts that will help them purchase coverage through an alliance. But the amount of the subsidy varies by proposal. If the subsidy amount allows people to enroll only in lower-cost plans, poor people may be relegated to substandard care if these lower-cost plans also turn out to be lower-quality plans, despite the requirement to provide certain standard benefits.

- **Risk Adjustment**: One feature common to all managed competition proposals, reducing risk-selection, makes health insurance more accessible but establishes a need to protect plans enrolling large numbers of high-cost users through a risk-adjustment mechanism. But risk-adjustment can be extremely complex, and there is little agreement about how best to approach the task.

Although risk-adjustment tends to be more feasible as risk pools get larger, purchasing cooperatives or alliances may not be large enough to sustain viable risk-adjustors, especially if membership is not mandated. Therefore, risk-adjustment — among individual health plans as well as among alliances — should be continually monitored and "re-calibrated" when necessary.

- **Emphasis on Primary Care**: Managed care systems generally provide more primary and preventive care, and this should help children with special health needs. But the "gatekeeping" mechanism can have negative consequences for children who require specialized services. This can occur because the managed competition model includes incentives for consumers to join cost-conscious, managed care plans that place a generalist primary care

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professional at the center of all care and service decisions.

Many children with special needs, however, require care from pediatric specialists. Some children with medically complex or rare conditions could go undiagnosed and untreated, other children may receive inadequate care, and still others may rely on their parents or guardians to try to negotiate the system and argue for more specialized services.

- **Choice and Continuity of Care**: The managed care system could benefit children by opening up new plan options. Financial incentives to choose lower-cost plans, however, could lead to severing long-standing relationships with individual providers.
  When a family joins a lower-cost HMO, it inherits the providers associated with that plan, which may not include a physician who has been serving a child for years. If families choose more "open" arrangements, they may seek care from providers who are not "in-network," but there are generally higher out-of-pocket costs. This may not be feasible for children with health problems if their families have limited resources.

- **Flexibility in Benefit Design**: There is growing awareness of the "interconnectedness" of physical, emotional, developmental, psycho-social, behavioral, and educational problems. Incorporating a broader spectrum of services for children with special needs could improve their overall well-being, as well as prove cost-effective in the long run.

  Reform proposals tend to steer clear of these "add-ons" as they may appear too costly. Yet health reform, particularly managed competition, could include reprogramming strategies that enhance flexibility in care management and reallocate resources to where they are most appropriate and effective.

**State Experience**

Managed care is not new to state Medicaid programs. Nearly all states now (or soon will) include a Medicaid managed care option. Despite the availability of such programs, children with chronic and disabling conditions have remained with traditional fee-for-service arrangements, although this appears to be changing in at least a few states. For example:

- Florida, Oregon and Iowa require managed care providers to refer, coordinate, contract or subcontract with public providers for select children's services;
• Virginia has established collaborative teams located in communities across the state to provide assessments and develop comprehensive service plans for children with complex needs and their families;

• Minnesota is setting up a system of voluntary Integrated Service Networks that will be prohibited from disenrolling individuals with high risks or special needs; the state also plans to increase Medicaid reimbursement rates to encourage provider participation in the programs.

Conclusion

It is important that policymakers carefully design a system that allows healthy children to receive preventive and primary care that maintains their health, while at the same time allows children with special health care needs to receive ongoing, complex and specialized services. It will be a challenging undertaking to build one system that accomplishes both of these goals. Yet it is those individuals with special health needs, particularly children, who will ultimately test the health care system's quality, efficiency, flexibility, and humanity. Policymakers cannot claim success in health care reform unless they protect the needs of this vulnerable group.
I. Introduction

This briefing report is written to alert public and private sector decision makers to the potential advantages and disadvantages of a “managed competition” health care reform strategy from the perspective of an important and very vulnerable population — children with special health care needs. While the focus of this report is on all children with special health care needs, it is important to note that a significant number of these children face the dual challenges presented by chronic illness or disability and poverty. Many children with chronic health problems are poor, near-poor, or “conditionally” poor by virtue of the staggering costs associated with their health problems. In fact, poor children are far more likely to experience severe health problems than their nonpoor counterparts. And many of these poor children with severe health problems have no health insurance. For example, as many as one out of every five disabled poor children is uninsured — twice the rate of nonpoor disabled children (McManus and Newacheck 1993).

The report poses critical questions that should be addressed in developing health care reform. Its purpose is to foster a deeper understanding of the current menu of health policy options so that each element is analyzed in light of its potential effects, both positive and negative, on children whose health status requires significantly more care than is generally required by “healthy” children. Despite its focus on children, many of the issues raised in this paper apply to other vulnerable groups as well, such as the adult disabled population, those with chronic illnesses, and many of the elderly population.

Before proceeding, we present a few cautionary notes about the scope of this report. It will not thoroughly evaluate the merits of a managed competition model or compare this model with alternative approaches such as single-payer systems. And, it will not predict which features of the various managed competition proposals are most likely to survive public and congressional debate. Instead, it starts with the premise that we are presently moving down a path toward a greater emphasis on managed care and managed competition, and this movement will be accelerated by various state health reforms, as well as whatever national reform plan emerges from Congress. It briefly describes the population of children with special health care needs, and illustrates how these needs translate into increased resource utilization. The report raises key questions about how the elements of a managed competition model should be implemented and adapted to best serve the interests and well-being of these children. And it examines certain initiatives by states to bring managed care to children with significant health problems.

This report lays the groundwork for two larger studies to be conducted by the Economic and Social Research Institute (ESRI) and the Maternal and Child Health Policy Research Center. ESRI’s study will respond to the questions raised in this
briefing paper by 1) focusing on the impact of a managed competition model on one particularly vulnerable segment of this population, i.e., low-income children with moderate to severe disabilities; and 2) analyzing those particular design elements in the model that could facilitate or impede the delivery of health care to these children. By contrast, the work of the Maternal and Child Health Research Center will cast a broad net around the entire population of children with special health care needs and present the key elements of alternative managed care delivery systems for these children under health care reform. Both studies, along with this initial report, are funded by the Annie E. Casey Foundation. This work is being coordinated by the National Academy of State Health Policy, which will play a lead role in disseminating the findings of our work.

Managed Competition and Managed Care

The United States stands poised to legislate and implement health care reform on a national level, even as reforms are being implemented in states and localities. A substantial amount of activity has coalesced around two related approaches: managed competition and managed care.

Managed competition is a way of reorganizing the health care delivery and financing system in which purchasers of health care negotiate with competing health plans on the basis of cost and quality. The strategy, which has yet to be tested on a large scale, pools groups of smaller purchasers of health insurance into larger purchasing conglomerates to spread risk more evenly among the insured, and to enhance purchasing power to hold down costs.

Managed competition involves new roles for government. Under all of the various managed competition proposals, government would provide subsidies for low-income people regardless of welfare status; set new rules for the insurance market to reduce risk selection; oversee some form of risk pooling; and require that health plans make information on their costs and health outcomes publicly available. To this basic core, some proposals add tax reforms, spending targets and caps, and mandates on employers and consumers to purchase insurance, or some combination of these measures.

There are three major legislative proposals garnering Congressional support that feature managed competition, although modified versions or combinations of these proposals are likely to appear over the coming months: the Clinton Administration’s Health Security Act; the Health Equity and Access Reform Today (HEART) Act, whose chief sponsor is Senator John Chafee [R-RI]; and the Managed Competition Act of 1993, a bipartisan proposal spearheaded by Representative Jim Cooper (D-TN).

While the three proposals differ in many important ways, all emphasize managed
care as the prominent health care delivery model. They all include incentives for consumers to make cost- and quality-conscious decisions that will ultimately lead them to join managed care networks. These networks generally coordinate services, stress primary care and prevention, and conduct medical management to deliver care in lower-cost, non-institutional settings.

A broad range of health plans could be construed as "managed care." They are often recognizable in the form of a health maintenance organization (HMO), which serves as insurer and provider, and accepts pre-paid, capitated payments in return for an accepted package of health services. Other plans that involve either less shifting of risk to providers or wider choice of providers, such as point-of-service (POS) options or preferred provider organization (PPO) plans, are also considered managed care.

Many of these plans exist around the country, and while a managed competition strategy is likely to accelerate their proliferation, they are already becoming a dominant delivery model, fast replacing the fee-for-service, strictly indemnity world of the past. In large part because of the cost pressures of the last decades, managed care has taken on a life of its own, separate and apart from national or state health reform efforts. Whether in the form of an HMO, a PPO, a POS plan, or a hybrid that includes a modified fee-for-service option, care will be managed in virtually all health plans of the future. And this is occurring without clear evidence that managed care models are appropriate for disadvantaged children, or for children with serious or chronic health problems.

**Impact on Children with Health Problems**

Several features of the managed competition model hold the potential to help children with health problems. First, the model contains incentives for consumers to enroll in a health plan that emphasizes coordination of services and continuity of care. Second, the insurance reforms included in the model would limit the ability of insurers to exclude high-risk patients, restrict their coverage, or charge exorbitant rates based on health status. Third, the model promises many people more flexibility in choosing the health plan that fits their needs, and offers health plans more flexibility in determining the most appropriate, cost-effective delivery options. Finally, the emphasis on measuring quality and provider performance and making this information available to the public should help consumers select plans with competent professionals.

A managed competition model, however, also holds some potential for harm for children with special health needs. Some of these negative "side-effects" are built into the incentive structure inherent in the model. Some arise if the model is implemented inappropriately. And others are common to any health reform plan that tries to hold down the growth of health care spending.
This report signals a warning bell by highlighting these negative side-effects. It challenges policymakers at the state and federal level to hear the concerns of children with health problems above the din of special interest groups engaging these issues. It argues for careful consideration of the potential consequences of reforms before they are implemented. It asks policymakers to thoroughly evaluate the potential impact of the managed competition model, its design features, its assumptions, and its expectations, on a group of vulnerable children whose care must be safeguarded.

II. Background: Children with Special Health Care Needs

Children's health problems include a wide range of physical, emotional, and developmental conditions, and many children face multiple and overlapping problems. Children with health problems experience varying degrees of activity limitations and require higher amounts of health care services than other children.

Nearly a third of all children under age 18 — almost 20 million kids — have one or more chronic (lasting or expected to last more than three months) physical, developmental, learning, emotional, or behavioral problems (Newacheck and Taylor 1992). The five most common chronic physical conditions are respiratory allergies, frequent or repeated ear infections, asthma, eczema and skin allergies, and speech defects (Table 1). In addition to these relatively common physical problems, children sometimes have conditions that are severe but low in prevalence, such as cerebral palsy, sickle cell disease, and diabetes. Most rare diseases are genetic and tend to appear at birth or in the first few years of life.

It is estimated that 20 percent of American children have had one or more developmental delays, learning disabilities, or emotional or behavioral problems during their lifetimes (Table 2) (Zill and Schoenborn 1990). National data reveal that 4 percent of children have been delayed in their growth or development and that delays are first noticed around the child's first birthday. They include temporary or limited delays associated with premature birth or early illness, as well as more severe and long-lasting disabilities related to chromosomal abnormalities, hereditary factors, perinatal infection, and other causes. Almost 7 percent of children have had learning disabilities. These are often identified when the child enters first grade, although they frequently appear in later years. For the most part, these disabilities
# TABLE 1
PREVALENCE AND SEVERITY OF SPECIFIED CHRONIC CONDITIONS AMONG CHILDREN UNDER 18

<table>
<thead>
<tr>
<th>Condition</th>
<th>Cases per thousand children</th>
<th>Cases in thousands</th>
<th>Percent Limited in Usual Activities Due to Chronic Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory allergies</td>
<td>96.8</td>
<td>6,155</td>
<td>12.3</td>
</tr>
<tr>
<td>Frequent or repeated ear infections</td>
<td>83.4</td>
<td>5,304</td>
<td>9.1</td>
</tr>
<tr>
<td>Asthma</td>
<td>42.5</td>
<td>2,700</td>
<td>28.6</td>
</tr>
<tr>
<td>Eczema &amp; skin allergies</td>
<td>32.9</td>
<td>2,088</td>
<td>10.5</td>
</tr>
<tr>
<td>Speech defects</td>
<td>26.2</td>
<td>1,666</td>
<td>33.1</td>
</tr>
<tr>
<td>Frequent or severe headaches</td>
<td>25.3</td>
<td>1,606</td>
<td>16.9</td>
</tr>
<tr>
<td>Digestive allergies</td>
<td>22.3</td>
<td>1,419</td>
<td>15.7</td>
</tr>
<tr>
<td>Other</td>
<td>19.8</td>
<td>1,256</td>
<td>24.7</td>
</tr>
<tr>
<td>Frequent diarrhea/bowel trouble</td>
<td>17.1</td>
<td>1,085</td>
<td>16.7</td>
</tr>
<tr>
<td>Deafness &amp; hearing loss</td>
<td>15.3</td>
<td>975</td>
<td>35.5</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>15.2</td>
<td>967</td>
<td>39.6</td>
</tr>
<tr>
<td>Heart disease</td>
<td>15.2</td>
<td>965</td>
<td>21.6</td>
</tr>
<tr>
<td>Blindness &amp; vision loss</td>
<td>12.7</td>
<td>810</td>
<td>19.4</td>
</tr>
<tr>
<td>Anemia</td>
<td>8.8</td>
<td>557</td>
<td>14.7</td>
</tr>
<tr>
<td>Arthritis</td>
<td>4.6</td>
<td>290</td>
<td>24.6</td>
</tr>
<tr>
<td>Epilepsy &amp; seizures</td>
<td>2.4</td>
<td>151</td>
<td>58.0</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>1.8</td>
<td>112</td>
<td>89.2</td>
</tr>
<tr>
<td>Sickle cell disease</td>
<td>1.2</td>
<td>74</td>
<td>15.2*</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1.0</td>
<td>64</td>
<td>30.0*</td>
</tr>
</tbody>
</table>

* Standard error exceeds 30% of estimate value


pertain to specific neurologic incapacities that cause exceptional difficulty in learning to read, write, or do arithmetic. And, 13 percent of children have
experienced emotional or behavioral problems. While these problems are usually first noticed at age seven, they peak in adolescence with an estimated 19 percent of 12-17 year olds affected. The most prevalent of these problems are attention-deficit disorder, phobias and anxiety disorders, childhood depression, and adjustment reactions to traumatic events.

**TABLE 2**

**CHILDREN UNDER 18 WHO EVER HAD DEVELOPMENTAL, LEARNING, AND EMOTIONAL PROBLEMS, 1988**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Delay in Growth or Development</td>
</tr>
<tr>
<td>All children</td>
<td>4.0%</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>2 years and under</td>
<td>4.3</td>
</tr>
<tr>
<td>3-5 years</td>
<td>4.4</td>
</tr>
<tr>
<td>6-11 years</td>
<td>4.1</td>
</tr>
<tr>
<td>12-17 years</td>
<td>3.6</td>
</tr>
</tbody>
</table>

* Ages 3-17


The impact of chronic conditions on children and their families is best described along a continuum, with some conditions associated with virtually no activity limitations and other conditions associated with severe and profound limitations. In 1991, 6 percent of children nationwide were described by their parents as being limited in their ability to participate in usual childhood activities due to one or more chronic conditions (Newacheck, 1994 forthcoming). The leading causes of activity limitation or disability in children are respiratory system diseases, primarily
asthma; mental retardation; orthopedic impairments, including deformities; and mental and nervous system disorders. These four conditions combined represent more than half of all disabilities affecting children.

Risk of disability or limitation of activity varies by condition, age, gender, and income (see Tables 1 and 3). Adolescents are almost three times as likely as preschool-age children to be limited in their activities. Children residing in families with incomes below the poverty level are 60 percent more likely to be disabled than children from families with incomes above the poverty level. Boys are almost 50 percent more likely than girls to be reported as having an activity limitation.

Since 1960, the prevalence of activity limitation or disability in children has tripled. This is due in part to advances in medical treatment, particularly newborn intensive care, extended survival of children with chronic conditions, and increased awareness resulting from better diagnostic tools as well as special education and early intervention programs (Newacheck, Budetti, and Halfon 1986).
### TABLE 3

PREVALENCE OF DISABILITY AMONG CHILDREN UNDER 18 YEARS OLD: U.S., 1989

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cases per 100</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>All ages</td>
<td>5.3</td>
</tr>
<tr>
<td>Under 5 years</td>
<td>2.3</td>
</tr>
<tr>
<td>5 to 11 years</td>
<td>6.1</td>
</tr>
<tr>
<td>12 to 17 years</td>
<td>7.2</td>
</tr>
<tr>
<td><strong>Poverty Status</strong></td>
<td></td>
</tr>
<tr>
<td>Below poverty</td>
<td>7.6</td>
</tr>
<tr>
<td>At or above poverty</td>
<td>4.8</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Boys</td>
<td>6.3</td>
</tr>
<tr>
<td>Girls</td>
<td>4.3</td>
</tr>
</tbody>
</table>


### Use of Health Services

Not surprisingly, children with chronic and disabling conditions experience medical and psychosocial service needs greater than those of healthy children or those with acute illness. Despite limitations in the data available to measure full resource utilization, national data do show that chronically ill and disabled children consume a significantly higher amount of health resources than other children.

Disabled children are costlier to treat on average than nondisabled children because they need more frequent, often complicated and/or specialized services. Conservative estimates indicate that total health care expenditures for children with disabilities are three times those of nondisabled children. Even within disability
categories, however, variation in health care expenses for disabled children can be substantial, and a relatively small group of disabled children accounts for a large portion of resources spent on care. National data show that 10 percent of children with limitations in their usual activity accounted for 65 percent of all health care costs for children (Newacheck and McManus 1988).

Compared to nondisabled children, those with chronic conditions that result in disability are far more likely to be hospitalized, obtain physician services, and use prescription medications, as shown in Table 4 (Newacheck and McManus 1988). Large disparities are also found in the use of other forms of health care. Services provided by physical and respiratory therapists, social workers, and psychologists are used six times more often by disabled children. Disabled children also use twice as many vision and hearing aids, orthopedic devices, and other medical transportation services. In addition, many children with chronic and congenital conditions often remain in newborn intensive care units and require surgical interventions and significantly higher amounts of nursing care when hospitalized, especially if they are under the age of 2. This accounts in large part for their higher hospital costs (Miller 1993).
<table>
<thead>
<tr>
<th>Health Services</th>
<th>Children with Limitation of Activity</th>
<th>Children without Limitation of Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital days (per 1,000 children)</td>
<td>1,739.1</td>
<td>441.9</td>
</tr>
<tr>
<td>Physician visits</td>
<td>5.1</td>
<td>2.8</td>
</tr>
<tr>
<td>Nonphysician visits</td>
<td>5.5</td>
<td>0.9</td>
</tr>
<tr>
<td>Prescribed medications</td>
<td>4.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Other medical services</td>
<td>0.4</td>
<td>0.2</td>
</tr>
</tbody>
</table>


A study of children's usage of physician services (Newacheck 1992) found that children with three or more chronic conditions are eight times as likely as other children to be high physician users (defined as ten or more physician visits the previous year). Children with activity limitations were more than four times as likely to be high physician users, and children with emotional or behavioral problems were twice as likely to be high physician users.

These numbers may understate the disparities, because many children with chronic conditions do not receive the services they require. Many chronically ill children are uninsured or underinsured, especially if they are also poor. For example, poor disabled adolescents (aged 10-18) are three times as likely to be uninsured as nonpoor disabled adolescents (Newacheck 1989).

Even among insured groups, lack of treatment remains a problem. Despite the alarmingly high lifetime prevalence of developmental, learning, and emotional
problems, for example, a substantial proportion of children have never received treatment for these conditions. According to parents, at least half of the children who had developmental or growth delays never received treatment or counseling. Among learning disabled children, 22 percent never received treatment. And among children with emotional or behavioral problems, 25 percent never received counseling.

III. Policy Issues

The architects of managed competition proposals at both the state and federal levels must weigh each building block to make certain that it supports the care of children with health problems. The goal is to construct a health reform proposal that retains the positive features of managed competition but counteracts the negative side effects inherent in the model. They must be especially careful to avoid developing a "Catch-22" system whereby the same incentives that discourage excessive care also set up obstacles to necessary, appropriate care. While the incentive to keep costs down may result in "underserving" across-the-board, this is particularly dangerous for children with moderate or severe physical health problems or with developmental, behavioral, or emotional problems because their conditions tend to require a more complex and intensive level of care.

Specifically, the features in any reform proposal must assure that children with special health needs:

1) receive quality care to prevent illness and support their physical and emotional development;

2) have access to the range and intensity of services required, regardless of whether their health problems are mild, moderate, or severe;

3) have access to, and the ability to continue relationships with, pediatric specialists with experience and expertise to recognize and appropriately treat their problems;

4) have access to services that are beyond traditional medical interventions but are essential to promoting healthy development.

Five critical elements of managed competition are discussed below, and key policy questions are presented that must be addressed prior to implementation. These and other features will be analyzed further in our subsequent research, at which time we will also offer recommendations to resolve these outstanding concerns.
ELIMINATION OF MEDICAID: Some managed competition proposals would mainstream the Medicaid population into purchasing cooperatives and alliances. This would remove the stigma of a welfare program from the process of receiving health care, but could also create some new difficulties for a population that may require significant non-medical services that have been provided through Medicaid.

The Medicaid program insures many of the nation's poorest people and provides access to a broad range of health services and professionals. The program can be labeled both generous and stingy: generous in the variety of services that it covers, and stingy in its eligibility requirements and reimbursement levels in many states. These restrictions affect both who can qualify for Medicaid coverage and how much physicians and other providers are reimbursed for treating Medicaid enrollees.

In part because Medicaid reimbursements are generally much lower than those for privately-insured patients or even Medicare recipients, and in part because Medicaid serves a low-income population, Medicaid recipients face significant barriers to treatment. Replacing the Medicaid program with a system of sliding-scale subsidies to which health plans would be blind (at least in theory) could diminish these stigmatizing barriers and enhance access to important health services. A disproportionate number of children with disabling chronic conditions are part of the Medicaid program. This occurs for at least two reasons: first, because poverty status correlates inversely with health status, especially for obstetric outcomes such as birth weight; and second, because "medical need" has come to be recognized by many states as a qualification criterion for Medicaid coverage. For years now, children on Medicaid, regardless of their health status, have been covered for a wide range of health and enabling services. Such services have included expanded preventive services for high-risk youth; physical, occupational, and speech therapy; and mental health counseling services. They have also included transportation to and from therapy and medical appointments, home visiting services, and multidisciplinary case management.

It is not clear whether these services would continue to be provided in a managed competition environment. This is critical for children who currently qualify for Medicaid either by virtue of their being poor or because of their being "medically needy," or both. Many of these children benefit enormously from these services under the current system. Eliminating Medicaid as a separate program could place these children in jeopardy. Under certain reform proposals, some of the "medically needy" could become uninsured, and ineligible for subsidies based solely on income. And, they may no longer qualify for "wrap-around" services, even if these services remain available to lower-income children.

Another critical issue concerning the Medicaid population is related to the type and extent of subsidies provided by the government. According to most of the leading
proposals, the poor and near-poor will receive public subsidies that will help them purchase coverage through a regional alliance. Depending upon the construct of the model, their subsidy will be based on the lowest-priced plan in a region (the Cooper proposal), the lower half of plans in the regional distribution of premium costs (the Chafee proposal), or the weighted average premium of the plans (the Clinton proposal). If all plans actually do provide the same benefit package and are of comparable quality, these restrictions may limit poor people's choice of providers, but will not necessarily have a negative impact on the quality of their care. If, on the other hand, subsidies are tied to the lower-cost plans and these plans are lower-quality plans, low-income people would be relegated to substandard care. It is possible that specifying a standard benefit package will not, per se, be sufficient to eliminate differences in quality among plans.

Policy Questions:

1. Should "wrap-around" services continue to be provided in a managed competition environment, and if so, who should be entitled to them?

2. If subsidies are tied to lower-cost plans, what safeguards are in place to make certain that poor people are not relegated to low-quality care?

3. If purchasing health insurance remains voluntary (as is the case under the Cooper plan), what happens to lower- and middle-income children who previously qualified for Medicaid solely because of their medical need?
RISK ADJUSTMENT: Reducing risk-selection makes health insurance more accessible but establishes a need to protect plans enrolling large numbers of high cost users.

The elimination of many insurance practices that result in individuals with existing or even pre-existing health conditions being denied coverage — or being assessed huge insurance premium rates — is unquestionably a positive step for families with children who have special health needs and is a cornerstone of any managed competition proposal. Insurance companies will no longer be able to "cream skim" only the healthiest, lowest-risk people, leaving those most in need of coverage either overburdened by its cost or completely out in the cold.

Managed competition, however, depends on the existence of many financially sound insurance companies and/or delivery networks to offer a range of services to subscribers. Disallowing risk-selection and rate-setting based on health status creates a major burden for the health plans with a disproportionate number of high-cost enrollees unless purchasing cooperatives or alliances accurately risk-adjust payments among health plans. Without accurate and fair risk-adjustment, over time, plans would not be financially able to treat people who need a lot of care. Just one or two very low birth weight babies, for example, could threaten a plan's ability to allocate care effectively to other enrollees.

But alliances and purchasing cooperatives do not currently exist on the scale envisioned by reform plans, other than on the drawing board. The newly-formed entities will require years to "gear up" to their roles as purchasers of care or adjusters of risk. To complicate matters, risk-adjustment can be extremely complex, and there is little agreement about how best to approach the task. Risk adjustment tends to get simpler as risk pools get larger and larger, and only two variables — age and sex — explain most of the risk variation among very large groups. Cooperatives and alliances, however, may not be large enough to sustain these risk-adjustors even in the long run, especially if membership is not mandated. To the extent that health plans are permitted to vary in price and/or benefits offered, there would be more danger of "adverse selection," with sicker people joining certain plans and healthier people joining others, exacerbating the risk adjustment process.

Some of these issues will be played out in the rate-setting process. Purchasing groups will request proposals from approved health plans, which will be required to offer a range of services and/or a level of care. Presumably, health plans will set bids that correspond to premium amounts that should take into account a certain number of high-cost users.

Regardless of what variables are included in the risk-adjustment formula, it should be flexible enough to allow "re-calibration" by the purchasing cooperative or alliance if flaws become apparent in its design or if it does not work appropriately. The onus of risk-adjustment should not, however, rest solely on the shoulders of the
individual alliance. Because this issue is so important to the financial viability of the system, a mechanism should be developed to make certain that there are safety valves not only for health plans, but also for alliances that are overwhelmed by high-cost users. Policymakers can decide in the coming months which mechanism might work best; a tax on all alliances to provide "emergency" funds for an overburdened alliance, or a reinsurance program financed through premiums are two possible approaches.

**Policy Questions:**

1) What adjustments should be available, especially in the first few years, if plans underestimate the number or cost of "sicker" enrollees who join the plan?

2) Should there be separate payment mechanisms for true outliers — whose exceptionally high costs would not be recaptured through a simple risk-adjustment scheme — through a risk pool, a reinsurance mechanism, or as an add-on to capitation?

**EMPHASIS ON PRIMARY CARE:** Managed care systems can provide more primary and preventive care, but the "gatekeeping" mechanism can have negative consequences for children who require specialized professional services.

One of the purported strengths of managed competition is its incentive structure that "nudges" consumers into cost-conscious, managed care plans. These plans embrace a primary care delivery model that places a generalist primary care health professional at the center of all care and service decisions. All of the enrollee's nonemergency care goes through this health professional, who keeps a watchful eye on use of specialist services. Generally, enrollees who choose this managed care option accept more limited access to specialists and receive more generous preventive benefits. This tradeoff works especially well for families who are healthy or who have relatively uncomplicated health problems.

Many children with special health needs are also well-served by this model. There are usually no limits on visits, minimal copayments, and — more and more — an attempt by the plan to improve continuity of care by assigning the patient a regular physician. This also helps to keep costs down, since the primary care physician can often treat the patient just as well as the specialist can, at lower cost.

By design, access to specialists requires referrals from the primary care physician — the so-called "gatekeeper" — whose inclination under a tightly-managed, capitation payment arrangement is to use primary care for most cases. Many children with special needs, however, require care from pediatric specialists. Some children with
medically complex or rare conditions could go undiagnosed and untreated because the required expertise to detect the problem is not available within the health plan. Other children may receive inadequate care, and still others may rely on their parents or guardians to try to negotiate the system and argue for more specialized services. Thus, when health plans discourage the use of specialists such as pediatric allergists or child psychologists or discourage children's hospitals in favor of general hospitals, experience that is tailored to the particular medical problems of children can be lost.

Even those children who do not require care from a specialist, but nevertheless require a lot more care than the average child, may find themselves bucking a system that is designed to hold down costs. For example, many HMOs screen inquiries concerning sick children by having a nurse respond to parents' telephone calls. Often, the parent is told to wait a few days, try a certain medication, or monitor the child and call back later. This contact with the nurse is generally a wise gatekeeping service that keeps children's routine visits to a minimum. This same service, however, may be inappropriate in the case of a child with special health needs, and the nurse may be poorly equipped to respond to more complicated illness or disability profiles.

Policy Questions:

1. Should the managed care system institute separate gatekeeping mechanisms for children with special needs, perhaps allowing them direct contact with a pediatric specialist?

2. If a plan includes cost containment incentives associated with having providers assume financial risk, how can it reduce the incentive to underserve patients by limiting their access to specialist services?

3. Are there sufficient training opportunities for primary care physicians to identify children with special health care needs who require referrals to specialty care?

CHOICE AND CONTINUITY OF CARE: The managed care system could benefit children by opening up new plan options; financial incentives to choose lower-cost plans, however, could lead to severing long-standing relationships with individual providers.

The expectation within a managed competition system is that more people will be offered a wider choice of health plans such as HMOs, PPOs, POS plans, and fee-for-service plans. Families could enroll in health plans tailored to their specific health
needs. Being able to select the most appropriate health plan could be especially helpful for families with children who require a wide range of health care services.

But the choice of health plan has financial consequences. Health plans have different prices and out-of-pocket costs that are generally tied to choice of provider. For example, when a family joins a lower-cost HMO, it "inherits" the providers associated with that plan, which may not include a physician who has been serving a child for years. Of course, every plan will offer the family other physicians in the same field. But continuity of care can be crucial in the case of children's illnesses and medical conditions.

A child with juvenile rheumatoid arthritis, for example, may have built up a relationship with a physician over more than a decade that allows the physician to be particularly responsive to the child's specific medical, therapeutic, and emotional needs, given the unique progression of the child's illness. For this child, physician care is just not fungible. On the contrary, a physician's experience with a patient over a period of years has "trained" him or her to recognize improvements or setbacks in the patient's illness, disability, or overall health condition. The value of this training is lost if the relationship between the physician and patient is severed. A family in which more than one member needs specialized health care faces a particularly difficult choice if each family member has developed long-standing relationships with providers in different health plans. In these cases, enacting legislation to allow all providers to participate in all plans, through so-called "any willing provider" laws, may not be the correct response to the problem. Making provisions for exceptional cases to seek care out-of-network is more appropriate.

If families choose more "open" arrangements, such as PPOs, POS or fee-for-service plans, they may seek care from providers who are not "in-network," but there are generally higher out-of-pocket costs. For individuals whose resources can accommodate this option, it provides the best of both worlds, since enrollees can take advantage of the benefits of the model and also seek specialized services from the provider of their choice. But managed competition proposals often tie their subsidies or employer contributions to low-cost plans, thereby limiting the choice of plans (and indirectly choice of provider) realistically available. Thus, the more flexible option may not be feasible for children with health problems whose families have limited resources.

**Policy Questions:**

1. How can the managed competition model retain its cost-containment incentives without sacrificing quality and continuity of care?
2. How should restrictions about use of network providers be adjusted to fit the special circumstances presented by many children with significant health care needs?

3. What provisions should be made for children with multiple health problems, or families with more than one child who requires different care arrangements?

FLEXIBILITY IN BENEFIT DESIGN: There is growing awareness of the "interconnectedness" of physical, emotional, developmental, psycho-social, behavioral, and educational problems. The health care system has traditionally rallied around the medical model, leaving behind vitally important — and often less costly — interventions that could improve health. The managed competition model has the potential to incorporate a broader spectrum of services for children with special needs to improve their overall well-being. Yet many managed competition proposals are not grabbing hold of this opportunity.

Managed care plans, with their emphasis on prevention and medical care management, could look beyond traditional medical services and take a more holistic approach to health care. By furnishing appropriate early intervention, developmental, and psychological services, by stressing counseling and drug and alcohol education and relapse prevention, by utilizing experienced public and private providers, by varying locations and treatment strategies to meet the needs of children and their families, and by establishing linkages with social and educational services, managed care plans could seek to improve the overall health of subscribers, including children with special health needs.

In our current system, many ancillary therapies and psycho-social interventions are not offered in physicians' office or hospital clinics. Private insurance, unlike Medicaid, often has failed to cover many of these services. And they are increasingly difficult to finance outside of the health care system, since they are parts of discretionary budgets (e.g., education, social services) that have been slashed — losers in the budget battle to such gainers as interest on the national debt and even health care entitlement programs. Most clinicians, researchers, social workers, teachers, and parents recognize, however, how important these services are to a child's health status. They are even more vital to children with significant health problems.

Managed competition proposals may steer clear of these "add-ons" as they may appear far too costly for current health reform efforts. Yet comprehensive health reform could reallocate resources from activities that are currently overfunded toward those that are underfunded. For example, at the same time that a third of the nation's hospital beds are empty on any given day, some adolescents still go without adequate substance abuse treatment because of lack of affordable and
available care. Redirecting resources to where they are needed most makes sense from an economic and social welfare point of view. Health reform should include these types of reprogramming strategies.

**Policy Questions:**

1. How can a managed competition approach build better linkages among medicine, public health, education, and social service systems and develop community networks that combine the widest variety of services to assure the healthy development of children?

2. What efforts should be undertaken to educate health plans and providers about the health benefits and cost-effectiveness of these non-medical services?

3. How can health plans provide these services economically, and how can they share some of these costs with agencies currently delivering social services that are not coordinated with the health system?

On balance, managed competition holds much promise, but also several potential problems for meeting vulnerable children’s health care needs. The point here is not to go back to the old days of "unmanaged care" or a "provider is king" model where bill payers ask no questions and set no limits. That is both unrealistic and unwise. Rather, we ask how a managed competition model can be structured to capture the gains for children and steer clear of the rough rocks. What safety valves need to be built into the model to protect children's interests? Our subsequent research will address these questions further and provide specific recommendations.

**IV. State Experience**

For over a decade, states have been experimenting with managed care in their Medicaid programs, largely in an attempt to balance access expansion with cost containment. As state officials witnessed large, annual increases in Medicaid budgets, many turned to managed care for the same reasons private interests did — to improve access to health care, to integrate the financing and delivery of care, and to control costs. These programs have met mixed success with respect to cost containment and access expansion.

Virtually all state Medicaid programs now include a managed care option, or intend to implement one during 1994 (Fox and McManus 1992; Simon, Chait and Rosenbaum 1994 forthcoming). These managed care arrangements vary from state to state, with some states offering Medicaid recipients more than one option: for example, 27 states have designed prepaid capitated plans, 21 states have fee-for-
service gatekeeping plans, and 16 states have programs that use a mix of these arrangements (Fox and McManus 1992).

Importantly, however, these managed care programs have typically not covered the subgroup of children with special health care needs arising from chronic and disabiling conditions. These children tend to remain with traditional fee-for-service arrangements (Simon, Chait and Rosenbaum 1994 forthcoming), where they receive more specialty care than state managed care programs generally provide. Even for non-disabled children in Medicaid managed care programs, there has been a decline in the use of specialists, a finding that underscores the concern that some children with special health needs might have difficulties receiving necessary specialty services in a managed care environment (Freund and Lewit 1993).

State Health Programs for Special Populations and Children

A few states are beginning to develop specific provisions to accommodate children with special health care needs in a managed care system. Some are experimenting with structural mechanisms to link private managed care plans and public programs to improve access and continuity of care for vulnerable children. These public programs include early intervention programs, maternal and child health programs, public health clinics, developmental disabilities services, school-based health programs, child abuse and neglect services, juvenile justice and delinquency prevention services, and community mental health and substance abuse systems.

Several states are requiring managed care providers to refer, coordinate, contract or subcontract with public providers for select children services. For example, Florida, Oregon and Iowa have encouraged managed care providers to subcontract with local health departments and federally qualified health centers for Medicaid recipients needing prenatal care or testing for sexually transmitted diseases. Iowa also requires that providers contract for family planning and maternal and child health services.

States are also experimenting with public entities becoming managed care providers. Florida is contracting with its Children's Medical Services (CMS) program on a prepaid capitated basis to provide comprehensive care for Medicaid children with special health needs, including those with disabilities. The CMS will be responsible for providing preventive, primary, and specialty care through its 10 primary care clinics, network of pediatric specialists and hospitals, and staff of case managers (Health Care Financing Administration, et al 1993).

In addition to building managed care capacity, states are creating collaborative structures across the public and private sectors to provide "wrap around" services and funding for special needs children. In California, a new program is being developed in Los Angeles County that integrates services for foster care children across three agencies: child protective services; health; and mental health. Children
entering foster care will receive comprehensive assessments, service plans, and case management services provided through seven regional treatment centers. Each center will include a network of providers to furnish preventive, primary and specialty care (Health Care Financing Administration, et al 1993).

Virginia has established collaborative teams located in each community across the state. These teams provide assessments and develop comprehensive service plans for children with complex needs and their families. In addition, teams manage funds allocated from a state pool that combines over $100 million in categorical funding for out-of-home placements across four public agencies (child welfare, education, juvenile justice, and mental health) (Code of Virginia 1993). Mechanisms for linking these collaborative structures with managed care and health purchasing cooperatives will need to be developed.

Minnesota, like other states such as Florida and California, is exploring new mechanisms for arranging or delivering primary, preventive, and acute health services. The Minnesota legislature recently authorized the creation of voluntary Integrated Service Networks (ISNs) by July 1994. These nonprofit or cooperative organizations will be prohibited by regulation from disenrolling individuals or groups with high risks or special needs (Riley, Mollica and Rydell 1994 forthcoming).

Minnesota’s program, known as MinnesotaCare, goes much further than other newly-designed cooperatives in safeguarding the health of children with special needs. In April 1993, a Minnesota Commission issued recommendations concerning access, quality, and financing for high-risk, high-cost, and special needs populations that include children with chronic illness and disability. The Commission stressed that ISNs must include providers who serve special populations and must pay rates commensurate with required service levels. After wrestling with the issue of whether to enroll specialists in multiple plans or to encourage specialty networks for people with disabilities, the Commission recommended that reimbursement rates be increased to encourage provider participation in mandated Medicaid and MinnesotaCare programs. Other recommendations include: 1) adjustments to limits on payments and expenditures through a risk pooling or reinsurance mechanism so that ISNs are not penalized for serving these populations (These adjustments would occur without a concomitant increase in premiums due to health risk or status.); 2) the development of performance indicators specifically for these populations; and 3) the formation of a broad-based working group to ensure advocacy, monitoring, and action on behalf of these groups (Riley, Mollica and Rydell 1994 forthcoming).

For populations with high-risk conditions and/or intense medical needs, the experience of states indicates that incentives to promote service efficiency through managed care plans must be balanced with protections against catastrophic
individual claims. There are a number of ways to limit risk, including capping total per enrollee expenditures per year or episode of illness for which the managed care plan is responsible, and removing certain diagnoses or categories of enrollees (e.g., high-risk newborns) from the capitation payment and reimbursing the managed care plan on a fee-for-service basis.

V. Conclusion

Health care reform on the national level appears to be moving toward a managed competition model that encourages the widespread use of managed care. The laudable initiatives in many states also indicate that there are efforts underway to expand the use of managed care. And many employers in the private sector are already developing and promoting managed care and cooperative purchasing arrangements. Indeed, such movement offers the potential to improve access, efficiency, and perhaps the quality of health care for a majority of Americans.

As discussed in this report, however, these initiatives may have unintended, negative consequences for specific segments of the population. Groups that consume a disproportionate share of health services, including children with health problems, are "at risk" as health care financing and delivery is reformed.

It is important that policymakers carefully design a system that allows healthy children to receive preventive and primary care to maintain their health, while at the same time allowing children with special health care needs to receive ongoing, complex and specialized services. It will be a challenging undertaking to build one system that accomplishes both of these goals, since its basic design will be developed in response to the needs of the general population. Yet it is those individuals with special health needs, particularly children, who will ultimately test the health care system's quality, efficiency, flexibility, and humanity. Policymakers cannot claim success in health care reform unless they protect the needs of this vulnerable group.
References


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The Economic and Social Research Institute (ESRI) is a nonprofit organization that conducts research and policy analysis in health care and the reform of social services. It specializes in studies aimed at improving the way health care services are organized and delivered, making quality health care accessible and affordable, and enhancing the effectiveness of social programs.

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*Improving Access and Quality of Care Under Medicaid Managed Care: Proposals for Reform* by Maureen Booth, Andrew Coburn, and Trish Riley. 33 p., January, 1993. Supported by the Henry J. Kaiser Family Foundation. ($15.00)

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