



## **Mandated Benefits: Essential to Children and Youth with Special Health Care Needs**

### **What are mandated benefits?**

Mandated benefits are health care benefits that any insurer must cover in a given state. States have passed laws mandating benefits to assure that people with health insurance are covered for specific kinds of treatments or providers. Often, legislators mandate preventive services such as screening that may save costs for the system as a whole by identifying conditions early, before they become severe and costly to treat.

In other cases, though, mandated benefits are designed to meet needs of particular populations at high risk. Some benefits are designed to serve children with special health care needs. These benefits may be needed by small numbers of children who would be at extreme risk if services or treatment were not assured.

There is no special pattern explaining which states mandate which benefits. Mandates usually reflect advocacy by citizens or legislators who see a gap in coverage and lobby to fill it. Often, however, when a mandate is implemented in one state, policy makers elsewhere look to that state as a model. Our intent here is to help stakeholders learn about mandates they might implement to improve financing of care in their own states.

### **Which mandates serve children and youth with special health care needs?**

Mandates are worded and structured differently from state to state. No one source of information covers all of them, but a good source to learn about some of the more common ones is the Kaiser Family Foundation at <http://www.statehealthfacts.org>. Through interviews with state informants, Catalyst Center staff have identified some less well-known mandates that are important for particular subgroups of children and youth with special health care needs. Some examples:

Florida has enacted a new mandate requiring coverage for treatment of craniofacial disorders. These are in-born structural anomalies of the face and

- skull. Treatment has been withheld for some children in the past when it is deemed “cosmetic.” The mandate addresses those exclusions. Texas has a similar mandate.
- Illinois mandates coverage for Early Intervention, which provides developmental services for children up to age 3 who show early signs of delay. Similar mandates in Arizona, Massachusetts, Rhode Island and Virginia assure that thousands of children receive developmental therapies during the critical period of early brain development.
- Hawaii, Texas and a number of other rural states mandate coverage for telemedicine. This makes it possible for families in remote areas to receive specialty care by linking primary care doctors to specialists in urban centers. It is a win-win investment, reducing the burdens of travel and time away from work for families, while improving care for their children without undue cost.
- Iowa, Wyoming and many other states mandate newborn hearing screening. In the past, only 50% of infants with hearing loss were identified at birth. Thousands of children grew up undiagnosed and untreated. New technology makes it possible to identify ALL newborns with hearing loss so all can receive early speech and language intervention. The result is the difference between major developmental delay and normal development again, for thousands of children.
- New Mexico, New York, Virginia and Maryland are among states that require coverage for nutritional products required by children who have inborn errors of metabolism. These are conditions for which screening (also paid for under mandates in many cases) is done at birth. Some of these inborn conditions can lead to severe retardation or even death if a child does not follow a special diet. Insurance mandates make it possible for families to purchase special foods that keep children alive, healthy and often able to function like their peers. These are rare conditions, but for affected families, these mandates are critical.

### **How do mandates work?**

Let’s look at one example. Massachusetts requires all payers, including Medicaid and private insurers, to pay for early intervention (EI) services for children 0 to 3. Because of the mandate, a pediatrician can refer *any* child in the state who shows signs of developmental delay or has risk factors (like prematurity or low birth weight) to a community EI program. If an assessment confirms that the child needs services, he or she can be enrolled regardless of the family’s income or coverage. Payment is assured and the EI program bills the family’s insurer. If a child is uninsured or if their costs go above a ceiling set by the state legislature, the state funds cover the difference.

This mandate does more than permit individual children to get services they need. It does that, and that's important. But beyond the individual, the mandate creates a financial base for a network of community EI programs, allowing them to hire skilled staff, provide staff training, purchase up-to-date equipment and supplies and maintain geographic coverage for all children. The result — 30,000 children are served yearly in a program that promotes optimal development during the critical early years and teaches parents the skills needed for raising children with a wide range of conditions and challenges.

### **Mandated benefits as a policy strategy**

These examples suggest the importance of existing mandates for individual families of children with special health care needs. But as mentioned above in relation to EI, mandates have systemic impact that goes beyond individual families and children. What are the policy implications of mandated benefits?

- Some opponents argue that mandated benefits make care so costly that they lead to reduced coverage and more people or employers unable to afford coverage. This concern is not borne out by the research: while mandated benefits (like any benefits) increase the cost of coverage, the link between the small increments added to cost by mandates and the number of people uninsured has not been borne out.
- Other opponents say mandates are not a good way to shape a system – they are too random and they contribute to fragmentation of our health system. It is true that mandates do not create systemic change. But they address fragmentation by linking the public health system to providers, payers and facilities responsible for health care delivery. If, for example, a state's policy makers want to make sure children can benefit from the new technology to identify hearing loss before it causes developmental delay, a mandate allows them to assure screening and follow-up even for newborns who receive care from private physicians in private hospitals.
- The Catalyst Center has identified four objectives to improve financing of care for children and youth with special health care needs. All four are facilitated by mandates, which help states:
  1. **Reduce underinsurance** by filling gaps in the typical benefit package. A mandate covering medically necessary food products is an example.
  2. **Reduce the uninsured population.** At least two states mandate coverage for categories of children with special needs who could otherwise be

excluded from private policies, leaving their families to struggle for basic care.

3. Assure payment for **wraparound services**. This is the term for care coordination, health education, respite and other services that help families get to and coordinate complex care their children may need. At least one state mandates respite coverage.
4. **Support the infrastructure** required for good care of children and youth with special needs. Telemedicine mandates are a good example of this; so is support Early Intervention described above.

### **The take home lesson**

1. You may have noted mandates listed here, or on a linked site, that could be replicated in your state. Call us, and we will help you find an expert with experience in that area.
2. Look into your state's mandate laws. You may be unaware of them, but current policy debates make it important to find out and flag them for policymakers who may not realize that some mandates are critical for children and youth with special health care needs.