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CATALYST CENTER
IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

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

What are mandated benefits?

Mandated benefits are health care benefits or services that any insurer must cover (see sidebar for an important exception). State governments generally issue mandated benefit regulations, although there is a selected group of mandated benefits issued by the federal government. Every state mandates at least some health benefits, or in some cases the availability of selected providers or the extent of available coverage. Other than the federally mandated benefits, policymakers in different states mandate a range of health benefits or services, depending on emerging issues in those states (Bunce, 2007).

Mandated benefits require state licensed group health insurance plans to include minimum levels of selected health care benefits (Gruber, 1992). 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 the needs of particular populations at high risk. Some benefits are designed specifically to serve children with special health care needs. These benefits may be required by small numbers of children who would be at extreme risk for adverse health outcomes if services or treatment were not assured.

There is no special pattern explaining which states mandate which benefits. Mandates usually reflect advocacy by citizens, professional associations or legislators who see a gap in coverage and lobby to fill it. When a mandate is implemented in one state, however, policy makers elsewhere may look to that state as a model.

The one exception to this rule involves coverage plans offered by big companies that "self-insure." Many large employers, as well as a few smaller companies contract with insurance or managed care companies to administer coverage for their employees, while using their own funds to cover employee health costs. Self-insured companies are exempt from all state mandates under the provisions of the federal Employee Retirement Income Security Act (ERISA) law. They may choose to comply with state mandates; but they are not required to do so.

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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 www.statehealthfacts.org. The specific language of mandated benefits is usually found in state statutes and can be identified through your state's insurance department or commission.

Through interviews with state informants, Catalyst Center staff has identified some less well-known mandates that are important for particular subgroups of children and youth with special health care needs (*The Catalyst Center Chartbook on Coverage and Financing of Care for Children and Youth with Special Health Care Needs*, 2007). These are some examples:

- Florida has enacted a mandate requiring coverage for treatment of **craniofacial disorders**. These are in-born structural anomalies of the face and skull. Payment for 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 most 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, 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 (Waisbren, et al 2003). These are rare conditions, but for affected families, these mandates are critical.

How do mandates work?

Let's look at a few examples. Hawaii mandates telemedicine, because pediatric sub-specialty services are not available on every island. Kentucky has a mandated autism benefit of $500 per year.

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, state funds cover the difference. Rhode Island has a similar mandate for EI services, with a $5,000 per year limit on claims.

These EI mandates do more than permit individual children to get the services they need. They do that, and that is a vitally important goal. But beyond the individual child, the mandate creates a financial base for a network of community EI programs, allowing them to hire and retain skilled staff, provide staff training, purchase up-to-date equipment and supplies and maintain geographic coverage for all eligible children. The result – in Massachusetts, for example, 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.

It is important to acknowledge that state-specific statutes determine the parameters of a particular mandated benefit. This results in variation between states and sometimes even variation between payers within a particular state. For example, if a state has mental health parity as a mandated benefit, it may mean unrestricted access to mental health benefits or there may be allowance for certain restrictions depending on the details of the statute.

Mandated benefits as a health policy strategy

Over the last two decades, as states have seen a proliferation of managed care health plans, there has been a concomitant growth in mandated benefits (Laugesen et al., 2006). In this context, mandated benefits may serve to protect valued health benefits or services that may be at risk of limits in an era of rapid growth in health care costs. In particular, mandated benefits target employer-sponsored health insurance plans and ensure that workers have access to benefits that plans or employers might be tempted to limit in an effort to control employer health care costs. (Laugesen et al, 2006).

There are several arguments that have been made against mandated benefits. Some assert that the economic strain of offering mandated health care benefits may compel employers to cut back by trimming health care coverage options or offering only part time jobs that are not associated with benefits at all in order to control health benefit costs (Jensen & Morrissey, 1999). The argument is that mandating health benefits may impact the ability of health insurers to offer affordable health care coverage options if mandates include benefits that carriers would otherwise not cover or would choose to cover with limitations not permitted under the mandate. Moreover, since

health benefits are part of an overall compensation package that is offered to attract top employees, some believe that employers would probably offer comprehensive health care benefits as they compete against other firms in the labor market. Thus, mandated health benefits are superfluous and burden employers as they must cover mandates even if the employer believes other benefits are more desirable to potential employees, and it is in the employer's best interest to provide comprehensive health care benefits anyway. (Jensen & Morrissey, 1999).

In contrast to some predictions, the perception of mandated benefits as a significant burden on employers does not seem to be influencing their behavior in terms of becoming self-insured in order to avoid offering comprehensive health benefits (Jensen & Morrissey, 1999). Additionally, 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 substantiated.[1] Finally, some have asserted that specific professional groups with an interest in receiving health insurance reimbursement have lobbied for mandated benefits; these benefits do not necessarily improve health care access for insured populations.

As mentioned on the front page of this brief, the federal Employee Retirement Income Security Act (known as ERISA) provided exemptions from mandated benefits for governments that provide health care benefits, such as benefits provided under Medicaid or Medicare. In addition, employers can decide to arrange for their own health care coverage through a process called self-insurance; self insured companies are also exempt from mandated benefits under ERISA. (Jensen & Morrissey,1999). For many years, the ERISA exemption has been followed, although a 2003 Supreme Court decision (Kentucky Association of Health Plans, Inc. vs. Miller, 538 U.S. 2003) may signal a change in this trend by potentially giving states the right to prevail over ERISA.

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[1]See, for example, http://www.consumersunion.org/health/testsw200.htm

There are four federally mandated benefits and these take precedence over the ERISA exemption for self-insured employers (Laugesen, 2006). While there are only four of them, the federally mandated benefits described below account for at least half of the costs associated with mandates (Bachman et al., 2008). They include:

- The Women's Health and Cancer Rights Act of 1998 (breast reconstruction and mastectomy coverage)
- The Mental Health Parity Act of 1996 (dollar parity for mental health benefits
- The Newborns and Mothers Health Protection Act of 1996 (hospitalization benefits after childbirth)
- The Pregnancy Discrimination Act of 1978 (parity coverage for pregnancy)

The importance of mandated benefits to children and youth with special health care needs, their families and the system of care

Mandated benefits are critically important for both children with special health care needs and their families. They provide specific health insurance benefit protection for children with high risk, low incidence and/or high cost conditions. While approximately 14% of US children have special health care needs (National Survey of Children with Special Health Care Needs, 2005), a subset of these children have rare disorders and require specialized treatment that may be prohibitively expensive for their families. Appropriately targeted mandated benefits ensure that these children have access to potentially life saving health care coverage.

For families of children with special health care needs, the risk of medical debt and financial hardship is reduced when a comprehensive array of mandated benefits is available. Those who argue against mandated benefits sometimes characterize them as providing services that are discretionary and that many families could fund out-of-pocket (Bunce, 2005). However, as documented in the Catalyst Center publication, "Payer of Last Resort: Medical Debt and Financial Hardship Among Families Raising Children and Youth with Special Health Care Needs", medical debt from out-of-pocket expenses is a real and serious problem for families of children with special health care needs.

Moreover, medical debt and bankruptcy due to out-of-pocket spending contributes to an inability of families to afford private insurance premiums, which in turn increases the uninsured. In addition, the impact of 'going without' also has cost implications to the system of care. For example, if a state mandates coverage for mental health services or autism, problems which are more expensive to treat down the line can be avoided or mitigated.

Mandated benefits offer advantages beyond those to individual children and families; it is important to re-emphasize the point mentioned above in relation to early intervention: mandated benefits that guarantee coverage for individual children with special health care needs often have positive system impacts for health care efficiency over the long term. In addition, mandated benefits can help address system fragmentation that disproportionately impacts children with special health care needs 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. Within these four objectives, we have identified the following ways in which mandates help states:

- 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.
- REDUCE UNDERINSURANCE by filling gaps in the typical benefit package. A mandate covering medically necessary food products is an example.
- 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 the complex care their children may need. At least one state mandates respite coverage.
- Finally, mandates help states SUPPORT THE INFRASTRUCTURE required for good care of children and youth with special needs. Telemedicine mandates are a good example of this; so is the support for Early Intervention described above.

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About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is a national center funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, and is located at the Boston University School of Public Health. The Catalyst Center provides support to the efforts of stakeholders at the federal, state and local levels in assuring adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families.

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