



The Importance of Integrated Services

A system of services is a family-centered network of community-based services that is designed to promote the health and well being of CYSHCN and their families. Ideally, community-based service systems are organized so families can use them easily. Care coordination, access to a medical home, family-centered and culturally competent services are considered key elements of coordinated services for families of CYSHCN. However, many families of CYSHCN face frustration accessing services. Eligibility requirements, policies, procedures, and multiple locations of services can leave families feeling overwhelmed. There are often gaps in services due to agencies that provide limited services or duplication in services from multiple coordinators and service plans. Families may also need to travel great distances to obtain specialized services.

The examples in the following sections, from medical home, care coordination, family-centered care, to cultural competency, as well as the common application forms found in the health information technology section, all address some piece of a coordinated system of care—although no state or community addresses all issues equally well. The following models of care often use strategies recommended by Champions for Inclusive Communities for developing coordinated services: including the use and development of interagency councils, partnerships with coalitions, supporting the development of family leadership and family-directed programs, and promoting linkages at the local and state level. For local level examples, please refer to the Star Communities on the Champions website: www.Championsinc.org.

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Financing of Care

Financing of care is one of the most challenging but important aspects of meeting the needs of CYSHCN. As a recent report from the Catalyst Center noted, “Families need a range of financing solutions to finally break the link between their children’s special health care needs and financial hardship. They need comprehensive health insurance, family supports and a broad investment in public health.” States are challenged by the pull of needing to develop a solid benefit package that will meet the needs of CYSHCN versus what is actually affordable. Yet, if families have access to adequate health insurance and financial supports, it is more likely that they will not be drowning in debt, family stress will be lower, and they will be participating in economic life.

While no state has or even claims to have an ideal financing system of care for this population, certain states have taken more proactive and in some case creative approaches to reduce the financial burden on these families either through Medicaid Buy-In programs, broad child health insurance programs, and other more directed financial supports. The models presented here demonstrate both system-wide health insurance approaches as well as more modest approaches that still make a difference in the lives of families with children with special health care needs. (For discussion of financing in Florida and other states, please refer to Overall System of Care).

Note: Each of the financing strategies below are deemed “emerging” practices since they represent relatively new mechanisms for financing and have insufficient data to demonstrate an impact on the CYSHCN population and their families.

ILLINOIS: COMPREHENSIVE HEALTH INSURANCE FOR ALL KIDS

Public/Private

System of Care: In 2000, Illinois launched its KidCare (CHIP) program for children in families with income up to 185% FPL. In 2006, Illinois became the first state in the nation to provide affordable, comprehensive health insurance for every child through its All Kids Program. Of the 250,000 children in Illinois without health insurance, more than half come from working and middle class families who earn too much to qualify for state programs like KidCare, but not enough to afford private health insurance. Through All Kids, comprehensive health insurance is available to every uninsured child, at rates their parents can afford. Parents pay monthly premiums for the coverage, but rates for middle-income families are significantly lower than they are on the private market. For instance, a family of four that earns between \$42,000 and \$63,000 a year pays a \$40 monthly premium per child, and a \$10 co-pay per physician visit. The program income limit goes as high as a Premium level 8 which allows income of \$14,701 or more a month for a family of four.

Evaluation: The All Kids program (KidCare has since been folded into the larger program) has helped reduce the number of families with CYSHCN without health insurance. In 2000, about 16% of enrolled CYSHCN were without any health insurance. With the inception of KidCare, the Illinois Title V CYSHCN program required every uninsured family to apply to KidCare in order to continue receiving financial assistance. The number of uninsured families has since

been reduced to about 5%. There are no particular or specific provisions in either KidCare or All Kids related to CYSHCN, but for much of their care, the program provides comprehensive healthcare coverage. As All Kids came into play around 2006, Illinois anticipated that with the same procedure of requiring families to apply for All Kids to continue receiving financial assistance from the CYSHCN Program, the number of uninsured children could be nearly 0%. This has helped the Illinois CYSHCN Program to save money and provide more financial assistance for families with health insurance where the health insurance does not cover or does not fully cover the cost (i.e., acts as a gap-filler for insurance). Illinois recently enacted legislation for a Medicaid Buy-In program as part of the Family Opportunity Act (FOA) but implementation has been delayed due to budget matters. FOA is part of the federal Deficit Reduction Act of 2005. Among the options it offers states are the ability to create a buy-in program to expand Medicaid coverage to children who meet SSI disability criteria and whose family incomes are too high to be eligible under current regulations but yet fall below 300% of the Federal Poverty Level (FPL). Medicaid buy-in programs allow some individuals or families who do not meet these income requirements, but meet other eligibility criteria, to purchase Medicaid coverage. They can “buy in” to Medicaid either as their only source of health care coverage, or as a supplement to private insurance.

Source in addition to expert interviews: All Kids website: www.allkidscovered.com; Frequently Asked Questions about the Family Opportunity Act’s Medicaid Buy-In Option. Catalyst Center. February 1, 2007. Accessed October 4, 2009. www.hdwg.org/resources.

MASSACHUSETTS COMMONHEALTH: MEDICAID BUY-IN

Public

System of Care: CommonHealth is a Medicaid buy-in program for CYSHCN (and adults with disabilities) who meet SSI clinical criteria but whose families are over-income for Medicaid. Family income is disregarded, and families pay a premium based on a sliding fee scale for either full or wrap-around

Medicaid coverage. There are no income limits on the program but the top premium amount is now \$600 per year. As a report celebrating the inception of CommonHealth more than 20 years ago notes, “Families of children with disabilities benefit from the CommonHealth program: they can work, stay married and not have to fear being forced to relinquish custody of their children with special health care needs in order to access Medicaid for them.”¹

Evaluation: Since Massachusetts implemented CommonHealth more than 20 years ago, Congress passed FOA in 2005. In addition to Massachusetts, Pennsylvania and Vermont also had some type of Medicaid buy-in program for CYSHCN prior to the FOA. To date, the following states have passed legislation to allow Medicaid buy-in through FOA: North Dakota, Louisiana, Illinois, Iowa, and Texas. However, implementation of the program in Illinois and Iowa has been delayed, apparently due to state budget issues. The Medicaid buy-in option represents a promising approach for states but is highly dependent on the quality of the Medicaid package families are buying into.

Will it Work in California: Budget problems may preclude California from pursuing this option as it has delayed implementation in other state such as Illinois. In addition, California will have to determine if its Medicaid benefits package meets the needs of CYSHCN. And, of course, such a program requires approval by the state legislature.

Sources in addition to expert interviews: Comeau, Margaret. Catalyst Center Presentation, September 25, 2008, “The Massachusetts CommonHealth Medicaid Buy-in Program at 20: A Retrospective and Celebration,” retrieved August 15, 2009. http://www.communitycatalyst.org/doc_store/publications/commonhealth_20_year_retrospective_aand_celebration_brief.pdf, Catalyst Center’s “Breaking the Link

¹ Comeau, Margaret. Catalyst Center Presentation, September 25, 2008, “The Massachusetts CommonHealth Medicaid Buy-in Program at 20: A Retrospective and Celebration,” retrieved August 15, 2009. http://www.communitycatalyst.org/doc_store/publications/commonhealth_20_year_retrospective_aand_celebration_brief.pdf

Between Special Health Care Needs and Financial Hardship,” February 2009 (www.Catalystctr.org).

SPECIAL NEEDS RELIEF FUNDS: NEW JERSEY, MASSACHUSETTS, MICHIGAN

Public/Private

Both New Jersey and Massachusetts offer Catastrophic Illness in Children Relief Fund funds for families in which families can apply for funds to handle catastrophic conditions in which out-of-pocket expenditures exceed a certain percentage of income. In Massachusetts, an expense qualifies as catastrophic if it represents at least 10% of family income. In this way, families have some assistance with the large purchases related to caring for CYSHCN (e.g., van conversion, home remodeling) that can pose such a burden on families. The funds are self-sustaining because they are funded by a \$1 per employee tax on employers who contribute to the state Unemployment Compensation Fund.

Michigan operates a similar type of fund called the Special Needs Fund, the oldest of the three, originally established in 1944 by a bequest to the state of Dow Chemical Stock. The fund operates solely off the interest from the stock. The fund helps families pay for large expenses such as ramps into homes as well as a parent participation program.

Additional approaches to reducing the financial burden on families not outlined in this section include such programs as specialized day care, benefits counseling, consumer directed benefits, care coordination and consumer-directed benefits/flexible spending accounts.

Will it Work in California: A regional pilot for this type of fund in combination with other programs such as benefits counseling and/or care coordination could be part of an overall approach to reduce the financial burden on families. A key issue would be finding a source to sustain the fund.

Sources in addition to expert interviews: Catalyst Center’s “Breaking the Link Between Special Health Care Needs and Financial Hardship,” February 2009 (www.Catalystctr.org).