

Financing Community Integrated Services

INTRODUCTION

Adequate financing of care for children and youth with special health care needs (CYSHCN) is a key policy objective in both the Healthy People 2010 objectives and the President's New Freedom Initiative. Despite this national commitment, over 40% of families of CYSHCN reported that they lacked sufficient health coverage as measured by the National CSHCN Survey (2001). Almost 1/3 of families of CYSHCN reported that their children were underinsured and lacked coverage for needed health services or therapies. 12% reported that their children lacked insurance coverage entirely at some point in the prior 12 months.

Inadequate financing of care for CYSHCN has a major impact on children, families and the system as a whole. For children, gaps in financing may mean that services are delayed or are foregone completely. For families, inadequate coverage may result in financial hardship, including bankruptcy. Health care providers report that lack of reimbursement is a major deterrent for CYSHCN to access to care within a medical home.

The following themes that address health care financing for CYSHCN were discussed by state teams at the 2005 Champions for Progress Multi-state meetings.

•**Relationships & Financing:** Relationships with new partners frequently pave the way to joint or expanded funding for specific programs or services.

•**Consumer & Provider Education:** Parents and providers who are knowledgeable about how legislative and regulatory funding decisions are made can protect critical benefit programs or promote expanded benefits where they are needed.

•**Maximizing Use of Existing Funding Streams:** Education of consumers and providers is key and knowledge of private and public health care financing and procedures that affect access (such as appeal procedures when services are denied) is needed.

EXPANDING COVERAGE TO UNINSURED CHILDREN

In Massachusetts, CommonHealth allows over-income families to purchase Medicaid coverage on a sliding scale. Families can purchase complete coverage or wrap-around services to enhance private insurance. Pennsylvania has a similar program.

In several states, state or county government pays for care of undocumented CYSHCN, while in others, local government funding supports community clinics that serve this population. These programs rely on word of mouth or parent-to-parent contact to inform families that services are available. In some states, volunteer physician networks provide specialty care for undocumented CYSHCN.

In several states, state funds may be used to cover premiums, co-pays or deductibles, allowing families facing financial hardship to maintain private insurance for their CYSHCN, such as COBRA insurance when parents have left work to care for a child.

FILLING THE GAPS IN COVERAGE

Alaska's Children's Hospital partners with Children's Miracle Network to conduct a telethon and raise funds to pay for services that are not covered by insurance.

In Iowa, public and private partners collaborate to fund care coordination for children served by the state's mental health carve-out provider, such as a community reinvestment grant from one of the state's managed care organizations.

California uses *managed care conversion funds* to help pay for services for CYSHCN. Funds are set aside for



public interest causes when managed care organizations convert from non-profit to for-profit corporations.

In Oregon, state agencies come together at the community level to address emerging issues. In some cases, agencies have supported care coordination and other community-based services provided by Title V.

In Rhode Island, families began to see restrictions in Medicaid funding for covered services (e.g. durable medical equipment) when the state faced shortfalls and tightened payment policies. As families became alert to cutbacks, they organized to protect children's access to these services.

Iowa Title V negotiated with Medicaid to cover chronic disease case management. While not as comprehensive as Title V care coordination, this coverage extends care coordination to more CYSHCN

Illinois Title V works with Medicaid to draw federal matching funds for care coordination provided to Medicaid enrolled children.

Washington State helps young adults with special needs use Social Security PASS funds to cover care coordination and other services that promote independence and employability.

In Idaho and Wisconsin, a systematic benefits screening process provides a comprehensive assessment of coverage options for families. This results in coverage for more children and ensures that safety net funds are reserved for children with no other coverage options.

STRATEGIES TO IMPROVE FINANCING

Indiana used graduate interns to develop a directory of transition services.

In California, children's health advocacy groups have used their own funds to take on issues that were not being addressed by state agencies. Funds came from federal grants, foundation grants, and organizational dues.

In Washington, the CSHCN program was awarded a Homeland Security grant to train law enforcement personnel on disability issues with a focus on techniques for working with individuals with mental illness.

In Rhode Island, parent advocates solicited funds from managed care organizations and a local bank to support conferences on Medical Home implementation.

In Alabama, Medicaid pays for travel by specialists to support training and backup for isolated rural providers. Rural providers in Alaska receive similar support from Children's Hospital in Washington State.

Nationwide, \$25 million has been appropriated under the New Freedom Initiative for Health Care Navigators to assist people with disabilities. Although their role is to help individuals, this can be seen as a way of expanding funding for care coordination.

States have partnered with large employers to set up information and referral programs for employees with CYSHCN. Employees get help to integrate private benefits and publicly-funded services for maximum effect.

FUNDING SOURCES

A wide variety of innovative funding sources (or innovative use of existing sources) were mentioned:

- Children's hospitals
- Local foundation grants, especially with a match to larger national grants
- Advocacy organization dues
- Social Security PASS program
- Work study funds and student internship programs
- Managed Care conversion funds
- Preservation of Title V funds by tightening enforcement of payer of last resort regulations
- Homeland Security grants
- CATCH funds (small grants from AAP for community systems enhancement)
- Contribution of time from local affiliate of National Public Radio
- Church funds used for partial support of a family consultant
- Use of state tobacco taxes and DUI fines (used in CO to pay for TBI services)

Useful Links and Resources:

ABC for Health: <http://www.abcforhealth.org/>

Catalyst Center: <http://www.hdwg.org/cc/>

MCH Policy Research Center: <http://www.mchpolicy.org/>

National Center on Financing for CSHCN: <http://cshcnfinance.ichp.ufl.edu/>

National Survey of CYSHCN (2001): <http://cshcndata.org/DesktopDefault.aspx>



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