

Topic: Know and share the laws, policies, procedures, and ethical principles that support and protect children birth to five with disabilities.

Bachman, S., Comeau, M., Tobias, C., Allen, D., Epstein, S., Jantz, K., & Honberg, L. (2012). State health care financing strategies for children with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 50*, 181-189.

Context

Although about half of the families of children with intellectual and developmental disabilities (IDD) are covered by private employer-sponsored health care coverage, families may also receive benefits from multiple public programs to supplement their coverage. The three key public programs that help fund health care for children with IDD are: (a) Title V Children with Special Health Care Needs (CSHCN), (b) Supplemental Security Income (SSI) through Medicaid, and (c) Children's Health Insurance Program (CHIP). Several other agencies can supplement coverage, including state departments of mental retardation, IDD, or mental health. Unfortunately, these programs do not adequately cover the costs of care for children with IDD and often families cut back on or stop work in order to meet the limited income eligibility criteria for benefits. There are also unusually long waiting lists for receiving Medicaid benefits because of the limited number of slots provided by program. The passage of the federal Patient Protection and Affordable Care Act of 2010 holds some promise for extending coverage for families of children with IDD. However, implementation of the new reform is still uncertain.

Purpose of the Study

The authors provide a "descriptive summary of selected programs developed to help expand the scope of coverage, mitigate family financial hardship, and provide health and support services that children with intellectual and developmental disabilities need to maximize their functional status and quality of life" (p. 181).

Method

Interview and survey data were collected from 47 Title V CSHCN directors, 35 Medicaid directors, and 22 representatives of Family Voices, a family advocacy organization with chapters in each state. The survey and interview questions focused on identifying strategies states use to finance health and support services for children with IDD.

Results

Outcomes that were reported indicate that families struggle to finance health care for their children with IDD. For example, 10% of these families did not have health insurance coverage at some point during the year of the survey, and 39.4% of families reported that their insurance was inadequate to meet their needs. Additional information gathered by researchers provided promising strategies that had potential to provide more coverage and reduce family financial challenges. The respondents identified a range of policy and program solutions currently in use at the state level, including the following:

- *Benefits counseling:* helping families navigate the complexities of health insurance.
- *Financing of care coordination:* hiring professionals to assist in linking various services and supports children need.
- *Consumer- and Family-directed care:* allowing families to decide how to use funds and services to meet their specific long-term care needs.

- *Flexible funding: trust and relief funds:* providing funds that can be used for services not typically covered by health insurance (e.g., catastrophic relief funds).
- *Mandated benefits:* ensuring that children with IDD who are covered by private insurance have access to selected benefits (e.g., preventative services, early intervention for children 0-3).
- *Medicaid buy-in programs:* providing families who are over the maximum income for Medicaid or underinsured to purchase Medicaid benefits for the child with IDD.
- *Specialized medical day care and respite and day camps:* providing care for children so that families maintain or return to employment.
- *Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) Medicaid eligibility option:* providing children who have hospital or institutional level care needs to receive services at home.

Discussion

States have a great deal of flexibility in how they design financing and support systems mandated by federal policy. As a result, support for families caring for children with IDD varies from state to state and some families are challenged by limited public benefits and fragmented systems of care. Promising solutions to these problems are identified in this article and the authors address different ways of adopting flexible financing programs that can assist families with higher routine costs of living and provide supports such as specialized day care that can help families minimize loss of employment income.

About Research-to-Practice Briefs

Research-to-Practice Briefs provide summaries of key studies that inform practice related to early childhood special education. The series is designed specifically to support community college faculty who prepare candidates to work with children with special needs in the early childhood setting.

About the ACCEPT Project

The ACCEPT (Advancing Community College Efforts in Paraprofessional Training) Project is a federally-funded cooperative agreement between the U. S. Department of Education Office of Special Education Programs (OSEP) and the University of North Carolina at Charlotte College of Education. The focus of this effort is the inclusion of special education content in the coursework and experiences provided within the associate degree program in early childhood education at targeted state-supported community colleges in North Carolina.

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