Lucile Packard Foundation for Children's Health

Fact Sheet

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Key Elements of Care Coordination for Children with Special Health Care Needs and Their Families

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In a 2012 survey, California families of children with special health care needs (CSHCN) identified care coordination as their top priority.[1] Children with special needs require care from a wide array of service providers, and as a result their care is often fragmented. Families report that they are not informed about available resources, are confused as to who is responsible for providing or paying for services, and are frustrated by the lack of planning, sharing of information, and comprehensiveness of care.

Care coordination can be a step toward resolving these issues. Done well, it addresses the interrelated medical, social, developmental, behavioral, educational, and financial needs of children and their families.[2] Care coordination is broader than case management, which focuses solely on the medical needs of patients.

Unfortunately, among families of CSHCN in California who need care coordination, nearly half report they do not receive it.

High-quality care coordination is proactive, planned and comprehensive, and it emphasizes cross-organizational relationships.[3] Its essential elements include:

- Services that are accessible and community-based;
- Use of a qualified care coordinator;
- Intake screening;
- Comprehensive assessment;
- Team-based development of a care plan;
- Family/patient-centered goal setting, planning, and services;
- Informing, arranging, and providing services, including advocacy and financing;
- Standardizing transmission of information among service providers;
- Monitoring service delivery and completing the feedback loop among services providers;
- Ongoing, trusting relationship between client and care coordinator;
- Enhancing the caregiving ability of patients and families; and
- Ongoing reassessment.

Care coordination is beneficial for families, for providers and for the health care system that serves them. In the pediatric setting, evidence indicates that providing effective care coordination services can improve the experience of care, improve the health of the population, and reduce costs.[4] Unfortunately,

among families of CSHCN in California who need care coordination, nearly half report they do not receive it.[5]

Improving California's System

Coordinating care for children with the most complex needs is a challenge, but California's system can be improved through strategies that address key issues:

Assessment

- Assess the *functional health status* of a child and family (in their home, school and community) to determine eligibility for care coordination services, rather than basing eligibility on diagnosis.
- Adopt an organized approach to identifying and employing information about health risks, using standardized assessment tools.
- Assess the family's capacity to participate in the implementation of the child's health care plan.

Quality Assurance

- Establish and adopt quality standards and measures for care coordination.

Service Provider Linkage

- Establish interagency coordinating councils at the county and state levels to resolve challenges, based on the California Community Care Coordination Collaborative[6] model.
- Co-locate services for CSHCN and their families.
- Enhance methods for information and data sharing across agencies.

Centralization

- Appoint regional care coordinators to provide interagency, system-level care coordination for the 1-5% of CSHCN with the most complex needs.
- Coordinate financing so that families interact with one system.
- Develop a shared plan of care with families and their team of providers.
- Establish a single point of contact that families interact with to coordinate their child's care.

Financing

- Advocate for recognition and payment of the CPT (billing) codes 99487-99489 for care coordination for patients with complicated, ongoing health issues, by state programs and third-party payers.
- Implement a Health Homes program[7] to provide care coordination for CSHCN with behavioral health care needs.
- Train and enable Family Resource Centers to bill Medi-Cal for providing care coordination and navigation services.
- Encourage payment of a monthly fee for Medi-Cal providers to coordinate care for CSHCN, based on the Medicare model that pays physicians a monthly fee of $42 to coordinate care for beneficiaries with two or more chronic conditions.

References

1. California Advocacy Network for Children with Special Health Care Needs: 2012 Survey Findings. Palo Alto, CA: Lucile Packard Foundation for Children's Health; 2012.

2. Antonelli R, McAllister J, Popp J. Developing Care Coordination as a Critical Component of a High Performance Pediatric Health Care System: Forging a Multidisciplinary Framework for Pediatric Care Coordination. Washington, DC: The Commonwealth Fund; 2009.

3. Ibid.

4. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health and cost. Health Aff. 2008; 27(3): 759-769.

5. http://www.kidsdata.org/topic/473/special-needs-care-coordination/table#fmt=627&loc=1774,2&tf=74&ch=833,834.

6. http://www.lpfch.org/cshcn/community-engagement.

7. http://www.dhcs.ca.gov/provgovpart/Pages/HealthHomes.aspx.

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health care through leadership and direct investment. The Foundation is a public charity, founded in 1997.

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