

Children With Special Health Care Needs: With Population-Based Data, Better Individual Care Plans

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Opinions expressed in these commentaries are those of the author and not necessarily those of the American Academy of Pediatrics or its Committees.

www.pediatrics.org/cgi/doi/10.1542/peds.2015-0319

DOI: 10.1542/peds.2015-0319

Accepted for publication Jan 28, 2015

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The author has indicated she has no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The author has indicated she has no potential conflicts of interest to disclose.

COMPANION PAPER: A companion to this article can be found on page e842, online at www.pediatrics.org/cgi/doi/10.1542/peds.2014-2431.

Children with special health care needs (CSHCN) represent 15% to 20% of all US children.¹ Several studies have documented well the substantial health care utilization,² school problems,³ and family financial costs,⁴ as well as decreased parental workforce participation^{5,6} and worse caregiver well-being⁶ for CSHCN generally and for a subset with more complex medical conditions. These effects are somewhat attenuated but not eliminated when families have access to practice-level primary care medical home programs⁷ and programs specifically targeting children with complex chronic conditions,⁸ and when stronger state-level safety net policies are in place.^{9,10}

In this issue of *Pediatrics*, Quach et al¹¹ accomplish 2 important goals that help to inform programs and policies to support families in caring for CSHCN using longitudinal population cohort surveys that incorporate the Children with Special Health Care Needs Screener.

Quach and colleagues describe 4 distinct trajectories of having a special health care need (no special health care need and transient, emerging, and persistent special health care needs) by analyzing data on 2 cohorts of Australian children collected in 4 biennial waves. They found that outcomes (learning, behavior, quality of life, and maternal mental health) are negatively affected, with emerging and persistent chronic conditions more strongly associated with progressively worse outcomes.

Their finding of a “dose effect,” that cumulative time spent having chronic conditions affects a child more than a transient condition, has potential implications for the delivery of services to CSHCN and is consistent with previous research detailing higher health service needs and expenditures and lower functioning for CSHCN with multiple conditions or more complex needs.^{1,2}

For services designed to support CSHCN, 1 size does not fit all. Although this is a long-understood concept, most tailoring of services aims to fit parent and family goals, the type of condition, and family and community cultural and social context, but not the expected course of a child’s condition explicitly. Because CSHCN with different trajectories have different outcomes, it would make sense that care plans would take this into account and entities that hold such programs accountable, such as medical home recognition programs and pay-for-performance initiatives, would allow for such care plan heterogeneity.

When a child develops a chronic condition, parents undergo an education about the health care system, disease management, and educational and social programs available to support their family. Parents appreciate guidance about a child’s expected path, particularly in terms of outcomes that matter to them. Parents’ time, finances, and mental efforts are valuable commodities, and unhelpful therapies are detrimental to family function. The more information about

trajectories and the outcomes that can be modified will allow parents to choose therapies, programs, and services that are most likely to help their children.

In doing so, it is worth noting that statistical predictions are helpful only as 1 piece of information in the complicated process of care planning. Parents, patients, and clinicians will take this information into consideration, as they do all other types of data regarding a child's expected course and response to treatment.

The above ideas can be implemented better if several research questions are further investigated. A clearer understanding of how the mechanisms and outcomes measured by Quach and colleagues can be modified by better support programs would inform the design of such programs. Trajectories are likely based in part on the specific condition, severity of that condition, and the child's response to therapy. Large sets of health data will continue to enable better prediction models, and potentially could be combined with other initiatives to incorporate genetic data in predicting a patient's course. With this important information, tailoring programs and therapies to not only family preferences and social context but also to the expected clinical trajectory can make delivery of health services and other support programs more efficient and therefore more valuable.

CSHCN are a population increasing in size,¹³ and much has changed in the years since the CSHCN screening tool was developed 15 years ago.¹⁴ Much more about this subset of children is known, and much of the knowledge gained has been translated into policies and

programs that provide real help and free parents to spend their time being parents, a role no one else can fill. As more is known about different subgroups of CSHCN, programs and policies can be better tailored to fit their needs and the needs of their families. Understanding the different trajectories CSHCN follow and the downstream effects allows clinicians and policy makers (and the families themselves) to understand what is expected, plan for the future, and choose the care that is right for them.

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Pediatrics 2015;135:e1040

DOI: 10.1542/peds.2015-0319 originally published online March 16, 2015;

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The online version of this article, along with updated information and services, is located on the World Wide Web at:

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