Once again, approaches to health care financing and access in the United States are being publicly debated, and once again, children’s health care is taking a back seat. On the plus side, some of the shortcomings of our current system are coming into greater focus, and fundamental questions about people’s right to health care and how to control health care costs are being voiced. On the other hand, the consideration of the social determinants of health, the social consequences of ill health, and the resulting health disparities (which are issues of special concern for vulnerable populations, especially developing children and children with special health care needs) have not entered the debate.

Among the approaches to controlling costs is a focus on the small group of individuals whose medical care accounts for a large portion of health care costs. This group, excluding older adults in their final years of life, tends to have complex medical and social conditions. Perhaps because most children seem to be in good health or because those who do not are few in number (and thus, cost relatively little), insufficient attention is paid to children with complex needs. Yet within the pediatric population, these children (who are characterized as having multiple, significant health problems that affect multiple organ systems; functional limitations; high health care use; and sometimes technology dependence) are most likely to manifest adverse outcomes when health and/or social services systems fail. The health and well-being of these most vulnerable of children are sentinel indicators of the effectiveness of the systems on which they depend.

By reputation, although absent much evidence, hospital and subspecialty care for children in the United States is world class. Ironically, the availability of technology and advanced care processes is contributing to the increased number of children with chronic and complex health conditions. Yet even among tertiary- and quaternary-care settings, there is substantial variation in who receives what care, how much it costs, and the outcomes achieved. Outside those settings, shortcomings in services for children with special health care needs are even more apparent; access to comprehensive, coordinated, and family-centered care is the exception rather than the rule.
Most of the problems in gaining access to quality health care are systemic, reflecting the additional time, skills, staffing, support, and payment that these children’s team-based care requires. Equally troubling is that many other problems arise from the longstanding fragmentation of services for children and families among physical and mental health, education, developmental disability and social services, and the failure to coordinate among them. Any family with a child with special health care needs can articulate the burden this places on their ability to care for their child.

In this supplement, we build on presentations and discussion from a symposium held in December 2015 at the National Academy of Sciences called “Designing Systems That Work for Children with Complex Health Care Needs.” The symposium, which was sponsored by the Lucile Packard Foundation for Children’s Health, was brought together in an effort to contribute to addressing some of the longstanding, systemic issues that affect the care of children with complex health conditions.

The goal of the Lucile Packard Foundation for Children’s Health is to improve the US system of care for children with chronic and complex health care needs. Our work is intended to ensure that all children have access to high-quality, culturally competent, family-centered health care when and where they need it, provided through a delivery system that recognizes their unique physical and developmental needs and potential. Our hope is that in the articles in this supplement, we can help clarify some of the difficult, systemic issues and challenges that affect health care for these children and point the way toward their resolution.

Throughout 2018 we will be hosting online discussions between the authors of articles in this supplement and key stakeholders in the field. Join us for the conversations or access the archived material at lpfch.org/aapsupplement.

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# Foreword

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