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Commentary

Opportunities for Improving Programs and Services for Children With Disabilities

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Optimal health care is achieved when each child and youth receives medically and developmentally appropriate care [1]. Increasingly, the goal of a planned health care transition from adolescence into adult care is recognized as key to maximizing lifelong functioning and well being for all youth, including those who have disabilities or other special health care needs [2,3]. Without adequate support, adolescents transitioning from pediatric to the adult health care system are at increased risk for poor health outcomes [1]. In fact, much of the health care transition history and professional expertise grew from the barriers encountered and experiences among youth with chronic health conditions whose families and providers sought to ensure that high-quality, developmentally appropriate health care services would be available in a continuous manner as the young person moved from adolescence to adulthood [1,4,5]. Over the past two decades, important professional resources have been developed to support effective transition services that are both important to youth with chronic health conditions, as well as among the broader adolescent community. These include clinical guidelines and recommendations on transition [1,6], new transition tools aimed at youth, families, and providers [7–10], and increased availability of medical homes [11]; all important in stimulating future improvements in transition performance [12].

Furthermore, specific strategies, such as the importance of pediatricians identifying or being part of a system wherein adult providers accept transitioning patients into their practices, particularly if the youth has medical comorbidities or disabilities, a focus on assuring uninterrupted health insurance coverage, enrollment in a medical home to improve continuity and wraparound services, and youth engagement in assuming greater responsibility for their health care, (if they are able) are noted as key to transition success [13–16]. Still, in 2016, only 15.7% of adolescents aged 12–17 with more complex health care needs received services necessary for successful transitioning to adult health care [17]. We note that adolescents who receive care in a medical home are more likely to get transition services (16.5% versus 13.2%) [17], highlighting the

importance of robust primary care. With the passage of the Affordable Care Act in 2010 and an increased commitment to expanding the numbers of children and adolescents accessing health insurance through their families, coverage rates have improved for youth [16]. Nonetheless, coverage remains a concern especially because health insurance adequacy decreases as children age to adulthood [17], and nearly a quarter of adolescents aged 12–17 years have special health care needs, while 11% have conditions that consistently and often greatly affect their daily activities [17].

Given the large numbers of youth in need of services and supports, a recent Consensus Study Report, developed by the National Academies of Sciences, Engineering, and Medicine, entitled, *Opportunities for Improving Programs and Services for Children with Disabilities*, placed special emphasis on the issues faced by transitioning youth with disabilities. The Report reviewed a number of findings and made conclusions that take into account the diversity of health conditions, disability severity, and need for supports and services reflected among children and youth with disabilities [18]. The Report concludes that long before they are ready for the transition, youth with disabilities benefit from regular access to and utilization of quality programs and services built on evidence-based strategies that positively impact health and functioning outcomes [18]. The wide variety of programs and services needed crosses multiple sectors, such as health care, education, social welfare, and employment. When optimized, programs and services are tailored to individual needs, goal-directed, flexible, and coordinated with other services [18]. Furthermore, they explicitly align short-term goals with long-term outcomes and conduct program evaluations to determine their success [18].

However, far from this ideal, youth with disabilities and their families often face a myriad of challenges in accessing programs and services, partly due to limited program and service availability, the complicated pathways to entry and to maintain services, and the effects of socio-demographic disparities. The Report provided numerous actionable conclusions. *First*, the diversity of needs also means that many youths with disabilities need services from a multitude of health and non-health programs that change across the lifespan that are not

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well coordinated, but could be. Thus, families are left to navigate a complex web of services and programs, often with little or no assistance, limiting their access to valuable services. *Second*, services are currently primarily organized and focused on short-term goals and outcomes. There is a crucial need to align these short-term services to long-term, strategic goals and outcomes focusing on vocation, long-term achievement, and independent living. *Third*, across sectors, there are a number of characteristics that effective programs and services for children and youth with disabilities share. These include being tailored to the child's and his or her family's specific needs, strengths, and interests; goal-directed; flexible; measurable; and coordinated with other services. Existing programs could focus their efforts on assuring tailored service delivery. The Report concluded that children and adolescents with disabilities need consistent access to services and coordinated and comprehensive supports, to achieve optimal function and preparation for adult life [18].

There are ample opportunities to further develop, implement, evaluate, refine, and scale-up programs and services to improve health and functioning outcomes for children with disabilities. A critical issue, however, is coordination and planning across the lifespan, from early childhood, through adolescence, and into adulthood. Addressing this need will require focusing on cross-system collaboration, interventions, and data collection and sharing to address these needs and promote valued adult outcomes, including health, post-secondary education and employment, community participation, self-determination, and independence. The Social Security Administration and other agencies, such as Center for Medicaid and Medicare, the Department of Education, Department of Labor, and other federal and state agencies, are in a position to support these outcomes, particularly through promoting cross system collaboration in the delivery of services and supports across the lifespan. They also have an opportunity to promote longitudinal data collection, sharing, and integration on program and employment outcomes that could provide new evidence of the impact of supports and services on long-term outcomes into adulthood. Policy makers and other stakeholders need to make a concerted effort to better coordinate the integration of supports and services and reporting of data on short- and long-term outcomes to make continuous sustained improvements in the lives of youth with disabilities. Multiple options exist for such coordination that need be further vetted through research and model demonstrations to make more fundamental systematic reform.

It is clear that all children and youth with disabilities deserve the chance to live life to the fullest. Now is the time to seize these opportunities and provide the support and services necessary to help them grow and thrive. Their success and the lessons learned in achieving the quality of life paves the way for all children and adolescents to benefit, as well as achieve effective life course care and successful transitions.

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