Advocates for adolescents and young adults (AYA) worked hard to make sure that the Affordable Care Act (ACA) met the needs of all AYA, especially those who are most vulnerable. Two articles in this month’s issue of the Journal of Adolescent Health present analyses on one vulnerable group, AYA with special health care needs (AYA-SHCN) [1,2]. Both articles demonstrate how these young people have benefited from the ACA and where they stand now with respect to access to care.

Focusing on AYA-SHCN serves several information needs. As a group, AYA-SHCN are particularly vulnerable to changes in the access to and the organization and delivery of healthcare. This group is often dependent on healthcare in order to reach their optimal health and well-being. They need and use considerable resources. Policy makers and practitioners need up-to-date information in order to develop and manage healthcare resources, including training of providers. Additionally, AYA-SHCN are an important group because they may be an early indicator of how changes in policy and delivery impact AYA more generally [3].

The dependent coverage provision of the ACA made it possible for young adults (YA) to remain enrolled in family insurance coverage until age 26. We know from many studies that this provision contributed substantially to the decline in the proportion of YA who are uninsured [4]. The article by Chan et al. in this issue contributes to our understanding of dependent coverage expansion specifically in the context of YA-SHCN [1]. Their findings illustrate the positive effect of the ACA. The proportion of YA-SHCN who experienced insurance gaps dropped from 48.3% before implementation of the ACA to 45.9% afterward, demonstrating that the dependent care provision is providing a pathway to better access to care for these vulnerable young people.

However, beyond the positive effects highlighted by the authors, several aspects of YA-SHCN’s access to care remain concerning. Nearly half of all YA-SHCN experienced a gap in insurance coverage over a 4-month interval even after implementation of the ACA. Periods of being uninsured leave YA with a decision between getting the care they need and incurring the substantial cost of care.

Other research on the ACA dependent coverage provision demonstrates that the benefits accrue disproportionately to YA with higher incomes [5]. Chan et al. do not specifically determine who among YA-SHCN benefits most [1]. If, however, extrapolating prior findings on YA generally to YA-SHCN specifically is valid, it is reasonable to be concerned that YA with SCHN and low income may not benefit at all from the ACA dependent care provision.

The Medicaid expansion provision of the ACA might be one way that low-income YA-SHCN could obtain coverage. States have the option to expand eligibility for Medicaid among low-income adults. Initially, in 2014, only 24 states expanded Medicaid. By 2016, seven more states had selected this option, and several other states are considering the change [6]. The extent to which Medicaid expansion has benefited YA-SHCN remains unclear and is worthy of further examination. There is a real possibility that services covered under Medicaid could be insufficient for YA-SHCN [3,7]. We need to know whether improved insurance coverage translates to improved access to and quality of care.

Having insurance is not synonymous with getting high-quality healthcare services. Others have called out provisions in the ACA that may limit the types and amount of services that YASHCN are able to use [3,7]. As advocates for AYA, it is incumbent upon us to look deeper into the impacts of what we do. As Chan et al. point out, there is still work to be done.

Also in this issue, Parasuraman et al. focus on healthcare utilization and unmet needs among adolescents with SCHN (A-SHCN) [2]. Utilizing the 2016 National Survey of Children’s Health, the authors show that nearly one in four (25%) adolescents in this nationally representative sample has a special health care need. This rate is higher than other national estimates made over the past 15 years, raising the possibility that SCHN are increasingly prevalent among adolescents. Furthermore, the prevalence of SCHN is higher among adolescents than it is among children under age 12. Clearly, the prevalence of SCHN increase with age into adulthood.

The primary focus of this paper, however, is on identifying the rates and determinants of A-SHCN’s unmet needs as a measure of the adequacy of the systems of care. Overall, 93% of A-SHCN use healthcare services, and slightly over 8% have an unmet need for care. Unmet need for dental care and mental health services are the most frequently reported. Other studies have demonstrated that these two vital services are difficult to obtain [8,9]. Having an unmet need is consistently associated with lower family income and lack of continuous insurance coverage. These findings are remarkably similar to those of Chan et al., supporting the concern

See Related Article on pgs. 435 and 445
that those already vulnerable because of an SHCN are additionally vulnerable when they grow up without the financial resources or protection of adequate and continuous insurance.

Together, these two articles bring to light new information regarding healthcare access among AYA-SHCN to which we must respond. Many AYA-SHCN still do not get the care that they need to optimize their health. American healthcare policy remains fluid, and it is critically important for clinicians, investigators, and those involved in public health and policy to continue to monitor both federal and state policies that have an impact on our young people.

PETER SCAL, M.D., M.P.H.
Department of Pediatrics
University of Minnesota
Minneapolis, Minnesota

References


