The Patient Protection and Affordable Care Act (PPACA) addressed the major issue of insurance coverage for young adults, the largest demographic of uninsured individuals. But for the significant numbers of young adults with special health care needs (YASHCN), the expanded coverage of the PPACA falls short of addressing problems around continuity of insurance, cuts in covered Medicaid services at age 18, inadequacy of coverage for transition and self-management visits, and incongruent provider networks while transferring care across systems. This article attempts to address some of these remaining challenges.

About 9.5 million young adults age 18 to 29, or one in five, has a pediatric-onset chronic medical condition or disability.¹ Until the recent passage of the PPACA, many young adults, including those with chronic conditions and disabilities, became uninsured once they turned 19 either because they aged out of their parents’ insurance plans or because they no longer qualified for public insurance. In Ohio, nearly 33% of YASHCN (age 19 to 26) did not have insurance compared to only 5% of children.²

When the PPACA was signed in 2010, private insurers were required to allow qualifying young adults up to age 26 to remain on their parents’ insurance plans. This resulted in coverage for an additional 6.6 million young adults who would not otherwise have been covered in 2011.³ Those with pre-existing conditions who were uninsured for more than six months became eligible to apply for insurance through temporary national high-risk pools. The more comprehensive coverage provisions of the law that will benefit young adults will go into effect in 2014. First, health plans will no longer be able to deny or drop coverage for people with pre-existing conditions. Second, Medicaid eligibility will be expanded to 133% of the federal poverty level (FPL) for all individuals under age 65. Finally, young adults whose employers do not offer insurance will be able to purchase insurance through regulated state-based health insurance exchanges with premium and cost-sharing subsidies for those who qualify. Starting in 2019, Medicaid will also be available to all former foster children up to age 25 who were in foster care for more than six months.⁴

However, the PPACA does not address many other critical issues related to the continuity and adequacy of insurance coverage, particularly when transitioning across health systems. First, YASHCN are particularly sensitive to disruptions in insurance coverage. The PPACA’s incremental approach to near-universal coverage has raised concerns that changes in income, employment, and family composition—which is the norm for adolescents and young adults—will shift young people into and out of different coverage arrangements over time, a phenomenon known as “churning.”⁵ Furthermore, young adult students with chronic conditions and disabilities may have difficulty maintaining school-based insurance since they are more likely to enroll part time and experience disruptions in attendance due to their illnesses. To address concerns about churning among low-income adults, some states are considering adopting a Basic Health Program (BHP) option of the PPACA. Under this option, states would receive a lump-sum payment equal to the cost of insurance exchange subsidies for households with incomes between the Medicaid cutoff and 200% of the FPL. The state would then assume responsibility for financing a BHP that contracts with Medicaid plans and providers to reduce coverage disruptions for low-income adults up to 200% of the FPL whose incomes rise or fall across Medicaid income eligibility over time.

Finding adequate insurance is also difficult for YASHCN. Medicaid is required to cover all medically necessary services and prohibits cost-sharing for children under age 18 because of rules under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. But when children turn 18, many of these services—including prescription drugs, dental care, durable medical equipment, and personal care services—become “optional” Medicaid-covered services that vary from state to state. Standard commercial insurance plans typically cover fewer of these services. As part of the PPACA, the Department of Health and Human Services has defined a set of 10 categories to be included in essential health benefits of all private and public plans, which now includes mental health services, prescription drugs, chronic disease management, and rehabilitative services and devices. Exactly what specific benefits states will include under these broad categories continued on page 2
is still unknown. But for YASHCN, inadequate coverage exacerbates their inherent heightened risk of secondary mental or physical health conditions.

For YASHCN, the greatest risk in becoming an adult is not financial in nature. Rather, it is the threat of institutionalization or of having basic health and daily living needs unmet if they remain in the community without personal care or other home health services. Despite recent policy changes that have expanded eligibility for these supports in the home and in community-based settings, access to these services is effectively limited by increasingly long waitlists. Promising options and state incentives exist within the PPACA to help address this problem: the Medicaid “Money Follows the Person” Rebalancing Demonstration Program, a state Medicaid option to provide home and community-based services for eligible individuals; the Community First Choice Option to provide community-based attendant supports and services to individuals with disabilities who require an institutional level of care; and a state balancing incentive program to increase the proportion of non-institutionally based long-term care services. While these options can help to address the chief risks of young adults with severe physical and mental disabilities as they turn 18, the extent to which states will choose to include these options in their state plans is unknown.

For medically complex patients followed by multiple specialists who are transitioning from pediatric to adult health care systems (assuming that adult primary care and specialist providers can be identified), their insurance plans may not be accepted by both pediatric and adult health systems concurrently. The incongruent provider networks may lead to interruptions in care, poor care coordination across systems, and poor provider-to-provider communication or subsequent collaboration. To help improve continuity of care among transitioning patients, some states—including Pennsylvania—have permitted eligible adolescent and young adult patients in capitated Medicaid plans to see both pediatric and adult primary care providers within a specified period. Other PPACA-funded health system performance initiatives, such as accountable care organizations, medical home demonstration projects, and the community-based Collaborative Care Network Program, have potential to decrease fragmentation of care for medically complex patients if they are carefully designed.

Finally, the PPACA mandated enhanced collection and reporting of data on a number of populations affected by health disparities, notably access and treatment data for people with disabilities. Coupled with the PPACA-formed Patient Center for Outcomes Research Institute, we have a unique opportunity to expand studies on the needs of young adults with chronic conditions and disabilities as they transition from pediatric to adult-centered systems.

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