

Patient Protection and Affordable Care Act of 2010 and Children and Youth With Special Health Care Needs

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ABSTRACT: The Patient Protection and Affordable Care Act (ACA) was designed to (1) decrease the number of uninsured Americans, (2) make health insurance and health care affordable, and (3) improve health outcomes and performance of the health care system. During the design of ACA, children in general and children and youth with special health care needs and disabilities (CYSHCN) were not a priority because before ACA, a higher proportion of children than adults had insurance coverage through private family plans, Medicaid, or the State Children's Health Insurance Programs (CHIP). ACA benefits CYSHCN through provisions designed to make health insurance coverage universal and continuous, affordable, and adequate. Among the limitations of ACA for CYSHCN are the exemption of plans that had been in existence before ACA, lack of national standards for insurance benefits, possible elimination or reductions in funding for CHIP, and limited experience with new delivery models for improving care while reducing costs. Advocacy efforts on behalf of CYSHCN must track implementation of ACA at the federal and the state levels. Systems and payment reforms must emphasize access and quality improvements for CYSHCN over cost savings. Developmental-behavioral pediatrics must be represented at the policy level and in the design of new delivery models to assure high quality and cost-effective care for CYSHCN.

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The Patient Protection and Affordable Care Act (ACA: Public Law No: 111-148, March 23, 2010),¹ the most sweeping health care regulatory reform in the United States since the passage of Medicare and Medicaid in 1965, was designed to move the United States toward universal and affordable health insurance coverage while simultaneously improving health outcomes and performance of the health care system. The legislation was enacted with minimal consideration for the distinctive needs of children.² Children and youth with special

health care needs and disabilities (CYSHCN), defined as “those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”³ are the subpopulation of children most likely to be impacted by the legislation because of their high health care utilization. CYSHCN constitute 13% to 18% of the population of the US children^{4,5} and include children with serious emotional disorders, estimated to be approximately 10% of the US population of children.⁶ Health insurance coverage for CYSHCN has been shown to improve access and utilization of health care services.⁷ Therefore, it is important to understand the law and its potential impact on this large segment of the pediatric population. This article reviews the rationale for the legislation and highlights provisions of the law as they relate to universality of coverage, affordability of coverage, and adequacy of care. It then discusses advantages and limitations of the ACA for CYSHCN. It concludes with priorities for advocacy on behalf of CYSHCN and implications of health care reform for the field of developmental-behavioral pediatrics.

RATIONALE FOR HEALTH CARE REFORM Pre-Affordable Care Act Context for the US Population

Many forces converged to necessitate health care reform in the United States. Health insurance has become

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essential for Americans, adults and children, to receive adequate medical care. Over the last several decades, costs of care skyrocketed because of dramatic advances in diagnostic procedures and treatments in the context of increasing life expectancy. High costs also reflected the impact of noncompetitive fee-for-service models in which physicians' income and hospitals' revenues are dependent on the number of patients seen and procedures done.⁸ The majority of Americans obtain health insurance through employer-sponsored plans. Leading up to Affordable Care Act (ACA), in efforts to control rising costs, health insurance companies denied coverage to individuals with preexisting conditions, rescinded coverage when an individual became ill, and reduced covered benefits. Employers also attempted to reduce their exposure by eliminating family plans and limiting options for employees. The number of adults without health insurance reached 42.5 million in 2010, and accounted for 16% of the population.⁹ Uninsured individuals typically missed preventive services and sought care only when medical issues could not be ignored. Urgent medical treatment was often more expensive than routine care. Medical expenses became the major cause of personal bankruptcy in the United States.¹⁰

Before the passage of ACA, publicly funded programs were the main alternative to employer-sponsored plans. Medicare provided universal health insurance to adults older than 65 years. Medicaid provided coverage to children, their parents, pregnant women, and individuals with disabilities who met strict financial eligibility. The State Children's Health Insurance Plan (CHIP), enacted in 1997, expanded insurance coverage to near-poor children whose family incomes exceeded Medicaid eligibility. Individuals without employer-based or public programs could buy health insurance in the private marketplace. Premiums were expensive, benefits limited, and costs variable based on health history and demographic features.

The United States is an anomaly among industrialized countries in terms of the high proportion of citizens without health insurance and the high expenses for health care. Table 1 compares the United States to selected industrialized countries. All of the other countries provide near or universal health services or health insurance.¹¹⁻¹⁶ Even for citizens with insurance, an extremely large proportion of the US population (41%) reported high out-of-pocket payments for copayment, deductibles, and other cost-sharing for general care, specialist care, inpatient care, and pharmaceuticals.¹³ Ironically, the United States spent more per capita on health care than countries with universal coverage¹⁷ and yet had less favorable outcomes in critical public health indicators, such as life expectancy¹⁷ and infant mortality.¹⁸

Pre-Affordable Care Act Context for Children and Children and Youth With Special Health Care Needs and Disabilities

Children and adolescents younger than 18 years in the United States account for approximately 23% of the US

population¹⁹ and about 10% of total health care expenditures.^{20,21} Before ACA, the proportion of uninsured children was about 7%,²² and uninsured CYSHCN was about 3.5% because they could obtain coverage through either private insurance, Medicaid, and/or CHIP.²² Health care expenditures for CYSHCN account for approximately 41% of total health expenditures for children, with children who are technology-dependent having the most expensive care.²³

Before ACA, CYSHCN experienced several challenges in obtaining health insurance. For example, in the private market in 2008, more than 20,000 children were denied individual health insurance because of preexisting conditions.²² CYSHCN often experienced discontinuity of coverage because of changes in parental employment or reaching annual or lifetime limits on benefits.²⁴ These CYSHCN with gaps in health insurance coverage were at increased risk for unmet medical needs, delays in receiving care, lack of a regular source of care, and not receiving well-child preventive care.²⁴⁻²⁶

Even when CYSHCN had insurance, families reported that they were more likely to have inadequate health insurance, that is, to be underinsured, than were other children in the United States.²⁷ As a consequence, the children received care that did not meet their needs²⁸⁻³⁰; they had difficulty obtaining specialty referrals; decreased satisfaction with care; and limited access to care coordination, a medical home, and community-based services.^{27,29,31} One significant example of unmet needs was mental health services, which were not included or adequately covered by many insurance plans.³² Only a small proportion of CYSHCN met optimal health care system quality indicators.⁴ CYSHCN experienced significantly higher medical expenditures than did other children, including out-of-pocket expenses.³³ Before ACA, families had no safeguards or limits on their financial obligation.³³

PROVISIONS WITHIN AFFORDABLE CARE ACT

Affordable Care Act (ACA) is complex legislation. Table 2 includes a list of terms and acronyms in the legislation. The provisions can be organized around 3 basic goals²²:

1. *Universal and continuous access to health insurance.* The 2 main mechanisms for increasing insurance coverage are (1) the creation of health insurance exchanges or online marketplaces for government-regulated and certified health insurance plans through which individuals can purchase affordable insurance and (2) expansion of Medicaid coverage.
2. *Affordability of health insurance.* The law specifies subsidies for the purchase of health insurance through tax credits for Americans with modest incomes. Additional subsidies are available for selected groups.

Table 1. The Overall Design of Health Services and Insurance in US and in Several Non-US Industrialized Countries

Country	Design ¹¹	PCP Receive Financial Incentives to Manage Chronic Disease or Complex Needs (%) ¹²	Coverage (%) ^{13,14}	Cost-sharing (Yes/No) ¹³⁻¹⁵	High Out-Of-Pocket Payments (% of Population Who Pay More Than 1000 USD in Past Year) ¹⁶
United States (before ACA)	Government programs Medicare: age 65+, some disabled; Medicaid: some low-income 60.5% of population buy private insurance (primary or complementary)	21	27.4 (public) 57.9 (private)	General care: Yes Specialist care: Yes Inpatient care: Yes Pharmaceuticals: Yes	41
Australia	Regionally administered, joint (national and state) public hospital funding; universal public medical insurance program (Medicare) 52.5% buy private insurance (duplicate or supplementary) for coverage of private hospital costs and noncovered benefits	75	100	General care: Yes Specialist care: Yes Inpatient care: No Pharmaceuticals: Yes	25
Canada	Regionally administered universal public insurance program (Medicare) 68% buy private insurance (supplementary) for noncovered benefits	70	100	General care: No Specialist care: No Inpatient care: No Pharmaceuticals: Yes	14
Germany	SHI system, with 134 competing insurers in a national exchange 31.9% buy private insurance (primary or complementary)	60	89.4 (public) 10.4 (private)	General care: Yes Specialist care: No Inpatient care: Yes Pharmaceuticals: Yes	11
Netherlands	SHI system, with universally mandated private insurance (national exchange) 89% buy private insurance (supplementary) for noncovered benefits	77	98.6	General care: No Specialist care: No Inpatient care: No Pharmaceuticals: Yes	7
Sweden	National health service <5% buy private insurance to cover private facilities (i.e., for elective surgery, specialist consultation)	49	100	General care: Yes Specialist care: Yes Inpatient care: Yes Pharmaceuticals: Yes	2
United Kingdom	National health service ~11% buy private insurance (supplementary) to cover private facilities (i.e., for elective surgery, specialist consultation)	50	100	General care: No Specialist care: No Inpatient care: No Pharmaceuticals: Yes	3

Types of nonprimary private insurance; complementary (covers cost-sharing left after basic coverage); supplementary (covers additional services); duplicate (provides faster access or larger choice to providers). PCP, primary care provider; SHI, statutory health insurance.

3. *Adequacy of coverage and care.* The law defines essential benefits in 10 categories that all plans must include. Prevention is emphasized.

Anticipating that a large influx of individuals into the health care system might result in steep rises in total health care expenditures, the law charged the Centers for Medicare and Medicaid Services (CMS) to develop new models of health care delivery that could improve quality while stabilizing or reducing costs. One model is the Accountable Care Organizations (ACOs), defined as networks of providers—doctors, hospitals, health professionals, and possibly other community resources and services—who share medical responsibility and cost of care for a defined group of patients. The ACO model predated ACA as an alternative to fee-for-service payment systems. Providers within an ACO share cost savings and, in some ACOs, are at risk for a portion of any spending that exceeds risk-adjusted targets. ACOs may use multiple mechanisms to achieve their quality and cost targets, such as implementing disease management programs or pay-for-performance arrangements, increasing the use of information technology, establishing medical homes, and/or using non-physician providers.⁸ ACOs are different from Health Maintenance Organizations in several ways: ACOs are run by providers, rather than insurers, reimbursement is tied to quality metrics, and patients can access providers outside of the ACO without a primary care referral. Studies of ACOs, which focus on Medicare recipients,⁸ have found that ACOs demonstrated improvements in health care quality but were variable in achieving cost reductions.^{8,34-36}

Health Homes are another alternative health care delivery model. Health Homes operate at the level of practitioner teams rather than networks. Health Homes offer person-centered and team-based care coordination for individuals with specific chronic conditions, notably mental health conditions and substance abuse.³⁷ The expectation is that Health Homes result in improved quality of care and cost reductions through decreased hospital and emergency department use. State-designated Health Homes receive an increased federal match compared with nondesignated providers. In a preliminary guidance, CMS stated that Health Homes should provide “whole-person philosophy, providing care beyond the individual’s physical or behavioral health condition to include creating linkages to long-term community services and supports, social services, and family services.”³⁷

ADVANTAGES OF AFFORDABLE CARE ACT FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES

Universal and Continuous Coverage

Affordable Care Act (ACA) creates the potential for more continuous coverage for Children and youth with special health care needs and disabilities (CYSHCN) through several provisions.¹ Expansion of Medicaid

means that additional CYSHCN may be eligible for public insurance (although in some states, children may be shifted from Children’s Health Insurance Plan [CHIP] to Medicaid). In terms of private plans, the law limits denial of coverage for preexisting conditions. It requires that an existing policy be renewed for anyone who meets the criteria for coverage, regardless of health status, age, or gender. These tenets assure that CYSHCN cannot be denied coverage when they initially sign up or when they seek to renew coverage. The law prohibits rescinding care when an individual gets sick, except in cases of fraud. This provision means that CYSHCN who develop complications or additional conditions continue to have coverage. ACA eliminates both lifetime and annual limits on the dollar value of benefits. The law extends dependent coverage on parents’ insurance plans to unmarried children until age 26 years. This provision eliminates a previously frequent gap in coverage for CYSHCN at the time of transition from pediatric to adult health care.

Affordable Coverage

Many of the provisions regarding affordability affect all Americans; those with high health care needs and moderate incomes are the most likely to be benefitted. The law specifies 5 categories or “metal levels” of coverage (e.g., bronze plan, silver plan) that differ in how individuals and health plans apportion the costs of care (Table 3). Importantly, premiums do not vary based on age, sex, or health status of the enrollee. This provision means that CYSHCN can get their insurance coverage at the same rates as the rest of the population.

The law provides subsidies for families to purchase health insurance coverage in the health insurance exchanges on a sliding fee scale as a function of family income and size. Families who earn up to 133% of federal poverty line (FPL) pay no more than 2% of annual income on premiums using tax credits; families who earn from 300% to 400% of FPL pay a maximum of 9.5% of annual income for coverage. Additional subsidies are available to low-income families who purchase a “silver plan” (Table 3).

An additional mechanism to enhance affordability is that health insurers are required to report publicly the percentage of total premium revenue that is expended on clinical services. Health insurance companies must refund enrollees if the insurer’s expenditures for non-claim costs exceed 20% in the group market and 25% in the individual market. Individuals and families have received “Medical Loss Ratio Rebates” based on this provision.

Adequate Insurance Coverage/Health Care

Affordable Care Act requires all plans to cover preventive services and immunizations recommended by the US Preventive Services Task Force and Centers for Disease Control and Prevention and certain child preventive services recommended by the Health Resources

Table 2. Terms and Acronyms for Understanding Provisions in the Patient Protection and Affordable Care Act

Concept or Construct	Acronym	Definition
Accountable Care Organizations	ACO	A network of health care providers who offers the full continuum of health care services for patients
Benefit Package		All of the services that are covered by an insurance policy or plan, including inpatient care, outpatient visits, and prescription drugs and any cost-sharing requirements or limits on services or spending
Centers for Medicare and Medicaid Services	CMS	Center for federal health insurance plans
Chronic Care Management		The coordination of health care and supportive services for patients with long-term conditions. Programs usually emphasize patient education, self-management, and use of evidence-based practices
Cost-sharing		Amount of money an individual spends when they use health care services (not premium payments), comprised deductibles, copayments, and coinsurance
Deductible		Feature of health insurance plans in which consumers are responsible for health care costs to a specified amount
Employer Mandate		Requirement to begin in 2015 for employers with >50 employees to offer affordable health insurance and pay a portion of those benefits or pay a penalty
Employer-Sponsored Insurance		Insurance coverage provided by employers to their employees and, in some cases, to the spouse and children of the employee
Essential Health Benefits		Comprehensive package of health and medical services within 10 categories
Federal Pay Line	FPL	Measure of income level used to determine an individual's eligibility for programs and benefits
Grandfathered Plan		A health insurance plan in existence on the date that ACA was established
Health Home		Organizations of services that integrate and coordinate all primary, acute, behavioral, and long-term services and supports for individuals with chronic conditions under a whole person philosophy
Health Insurance Exchange		A state-based competitive health insurance market where individuals and small employers can shop for health insurance plans
Medical Home		A health care setting in which patients receive comprehensive primary care services; care coordination, and access to other health care services
Medical Loss Ratio	MLR	Percent of premium dollars that a health insurer spends on direct care for patients and efforts to improve health care quality, as opposed to administrative costs or profits. If MLR is less than 85% for large insurers and 80% for individual or group insurers, then enrollees get reimbursements
Minimal Essential Coverage		Coverage that an individual must have to meet individual responsibility under ACA
Qualified Health Plans		Health plans offered through exchanges that have been certified or accredited by state law
Risk Adjustment		Process of increasing or reducing payments to health plans to reflect expected spending and compensate health plans that enroll patients who have more health conditions
Underinsured		People with health insurance who face expensive out-of-pocket costs or limits on their benefits

ACA, Affordable Care Act.

and Services Administration. Although this requirement may not represent a major change for those insured children whose insurers previously followed federal preventive care federal guidelines, the provision ensures that all plans qualified under ACA are held to the same basic standards.

Affordable Care Act has defined a set of essential benefits in 10 categories³⁸ (Table 3). Pediatric services

include dental care and vision services, an improvement over most previous plans. Maternity benefits are classified as preventive services and must be provided at no additional cost.³⁹ Mental health, rehabilitative, and habilitative services and medical equipment are particularly favorable for CYSHCN. Before ACA, only 2% of individual health plans provided benefits in all 10 essential benefit categories, and, on average, plans offered 76% of

Table 3. Five Categories of Health Insurance Plans with Insurance Contribution and Personal Responsibility for Health Care Expenditures

Plan Name	Insurance Contribution, %	Personal Responsibility, %	Comments
Bronze	60	40	Least expensive plan, appropriate for healthy individual anticipating no major illness or medication need
Silver	70	30	Considered best value. Families may qualify for lower out-of-pocket expenses based on household size and income only with this plan
Gold	80	20	For individuals with high levels of doctor visits or regular prescriptions
Platinum	90	10	Highest monthly premiums and highest coverage. Appropriate for families with high health care needs
Catastrophic	<60	All health care costs until threshold is reached	Available only to <30 yr olds or those with hardship exemption

the benefits that are mandated under ACA (Table 2).³⁹ A recent study of the Massachusetts experience after passage of health insurance on which ACA was modeled found a modest increase in access of CYSHCN on private plans to specialist care but no change in access to primary care.⁴⁰

LIMITATIONS OF AFFORDABLE CARE ACT FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES

Exemptions From Many Affordable Care Act Provisions in Grandfathered Plans

Private employer-based health insurance plans that were in effect when Affordable Care Act (ACA) was signed into law are considered “grandfathered” plans and remain exempt from many of the law’s provisions as long as they continue to exist. The exemptions include annual and lifetime benefit caps, provision of essential benefits, and requirements for well-child and preventive care. In the past, these grandfathered plans covered between 45% and 55% of children and youth with special health care needs and disabilities (CYSHCN).²² Grandfathered plans severely limit the law’s reach toward universal, continuous, affordable, and adequate care for CYSHCN.

No National Standards for Essential Benefits

The Secretary of Health and Human Services did not issue national standards for the 10 essential benefit categories as part of the law or subsequently. Instead, states and their insurance plans were allowed enormous autonomy in creating specific definitions for essential benefits.⁴¹ Their definitions can be based on previous marketplace standards, rather than on scientific evidence or clinical best practice guidelines. The variation in benefits among plans and states may be substantial.⁴¹ The benefits for CYSHCN, which are covered through the exchanges, may prove far less generous than standards through the Early Periodic Screening, Diagnosis, and Treatment Program (the child health

component of Medicaid).⁴² The standard of medical necessity, which governed which benefits are considered essential, was extremely difficult to apply in the pre-ACA era; ACA provides no further clarity on the definition of medical necessity. Although rehabilitative and habilitative services are listed as essential benefits in ACA, the absence of regulation and national consensus means that services that are important to CYSHCN may not be covered.

Elimination of or Reduced Funding for State Children’s Health Insurance Plan

Affordable Care Act authorizes Children’s Health Insurance Plan (CHIP) only through 2019. The federal goal is to fold children’s health insurance into market plans offered in the private sector and exchanges. CHIP has filled an important gap in health insurance coverage for poor and near-poor children who have not been eligible for Medicaid,⁴³ although evidence about the impact of these programs on health status is limited.⁴⁴ The loss of CHIP could negatively affect universal coverage, affordability, and adequacy of health insurance for CYSHCN. CHIP programs have greater protections against cost-sharing than do child-only health plans offered in state exchanges.⁴³ Less than half of the children in CHIP programs will likely qualify for cost-sharing subsidies or premium tax credits.⁴³ It is not yet clear how benefits under CHIP will compare with the benefits under qualified health plans but early studies find that CHIP offers more generous benefits packages.⁴³ Thus, without the continuation of CHIP, CYSHCN may lose critical benefits while incurring increased cost.

Although authorization of CHIP continues to 2019, ACA extends funding for CHIP through October 1, 2015. If funding is reduced or eliminated in 2015, then the number of uninsured children will likely increase and may double, resulting in coverage for this population that could be worse after ACA than before.⁴¹ It will be critical to watch national trends to assure that the proportion of CYSHCN with health insurance is not worse after implementation of ACA than it was before.

Limited Experience With Accountable Care Organizations for Children and Youth With Special Health Care Needs and Disabilities

Pediatric Accountable Care Organizations (ACOs) are unlikely to achieve cost savings to the same extent as adult or population-based ACOs because children are relatively healthy and spend less on health care than adults. Moreover, the prevalence of CYSHCN is higher among the poor and racial and ethnic minorities than among the middle class and majority groups. Pediatric ACOs will need to address health issues related to low socioeconomic status and will need to emphasize culturally competent services. Thus far, most ACOs have focused on Medicare recipients with chronic conditions; the expectation that the ACO model will yield cost reductions in health care for children or CYSHCN may prove unreasonable.

Pediatric ACOs may take several different forms to achieve integrated health care delivery, each of which anticipates cost reductions from different causes (Table 4).⁴⁵ In one form, children with chronic conditions would be served through family-centered medical homes, similar to the model promoted by the American Academy of Pediatrics.⁴⁶ In a second form, all children would be included. A third form would include adults, families, and children. A fourth form would integrate health services with a broad spectrum of educational and social services for children and families.⁴⁷ Extensive research is required to determine which Pediatric ACO forms achieve the best results in terms of quality and cost reduction.

The Pediatric ACO Demonstration Project that was supposed to be implemented between 2012 and 2016 has faltered because of lack of federal funding. However, Medicaid-funded ACOs have been developed in several locations, including Nationwide Children's Hospital, Rainbow and Babies Children's Hospital, Mercy Children's Hospital, and in the state of Oregon.⁴⁸ Limited uptake of the Pediatric ACO model in other locations has been attributed to poor direction and limited funding.⁴⁹ The Children's Hospital Association (CHA) is floating a proposal to create a Pediatric ACO for children on Medicaid with medical complexity, defined as at least 2 medical conditions, with children's hospitals as the hub.⁵⁰ The current ACOs and the CHA proposal all have the advantage of preserving regionalization of pediatric health systems for high intensity or complex care. A regionalized approach has achieved better health outcomes than deregionalized systems for children with complex problems, such as those cared for in neonatal intensive care units.⁵¹

Lack of Tested Models for Health Homes

The Health Home has a much broader mandate than the Medical Home. Pediatricians have become highly familiar with the concept of a medical home based on the policies of the American Academy of Pediatrics supporting their implementation.⁴⁶ Table 5 contrasts the

2 concepts. Importantly, Health Homes are intended for Medicaid populations and focus on individuals with mental health conditions and substance abuse, as these conditions represent the most costly health problems.⁶ The Health Home provides linkages to a broad range of community and social supports that serve individuals with these conditions.

The concept of Health Homes for children on Medicaid with severe emotional or mental conditions has merit. The challenge of establishing Health Homes for this group is that the care of mental and emotional disorders is different in pediatric and adult populations. Mental health care for children requires more face-to-face contact, less telephone management, and more intensive family support and training than does comparable care for adults.⁵² Community linkages are quite different for children compared with adults. Children with severe emotional disorders are often involved in child protection services or juvenile justice systems.⁵² Client-to-staff ratios are much lower in programs working with children than with adults, and, at present, care coordination providers in systems for adults receive lower reimbursement than comparable providers in the child health system.⁵² These factors combine to make behavioral health services for children more expensive than services for adults.

The Health Home construct may work for CYSHCN beyond those with mental and emotional disorders. The conceptualization that primary care physicians must create linkages with a broad range of community supports and services beyond health care could improve the overall functioning of CYSHCN. However, a new Health Home model, predicated on best practices for CYSHCN and not simply a simple modification of the adult model, would be a prerequisite. Research on child and family outcomes as a function of different medical home models, Health Home models, and care coordination models should proceed to define the distinctive requirements of care for CYSHCN. In addition, studies will be needed to establish the appropriate rates for the care of CYSHCN in Health Homes. Failure to appropriately adjust reimbursements based on risk status for CYSHCN would almost certainly result in limited interest among child health providers in offering Health Homes.

IMPLICATIONS FOR THE FUTURE

Current Status

As of the writing of this article, the proportion of uninsured Americans has dropped since implementation of Affordable Care Act (ACA).⁵³ Many states and the federal government established health insurance exchanges for individual and small business consumers; we are in the second year of enrollment. The Supreme Court decided in the case of *National Federation of Independent Business et al versus Sebelius* (February 2, 2012) that the individual mandate to purchase insurance was constitutional, but that the federal government could not withhold federal Medicaid funds if states elected not to institute Medicaid expansion. This ruling

Table 4. Accountable Care Organization Forms that Include Children and Youth with Special Health Care Needs and Disabilities

Form	Provisions to Improve Care and Health Care Service
1 Medical homes	Emphasis on care coordination within an integrated system Anticipation of fewer emergency room visits, unplanned hospitalizations, and duplication of services
2 All children	Shift to primary care management of common conditions such as attention-deficit hyperactivity disorder and asthma Use of alternative providers Integration of behavioral and physical health into seamless system
3 Adults, families, and children	Anticipation of improvements in quality of women's health and infant outcomes Simplification of transition of youth to adult systems
4 Health services integrated with a broad spectrum of educational and social services for children and families	Investments in early childhood education and family support services Integration of clinical or traditional public health outcomes with broad indicators of child and family well-being Reduction of public expenditures through lower costs in child welfare and juvenile justice systems

effectively gave states the choice about whether to expand Medicaid. Many governors, primarily in the Midwest and South, opted against expansion, reducing the progress toward universal coverage. Finally, after ACA, the growth in per capita costs of health care has slowed significantly.⁵⁴

Legislative challenges continue in the current US legislature. One proposed bill would redefine full time work for the purposes of calculating the number of workers in large corporations who must be offered employer-based insurance coverage. In addition, a pending Supreme Court case challenges the provision of subsidies to individuals who purchase insurance on the federal rather than state insurance exchanges. Either of these changes could limit access to or affordability of health insurance.

Even if ACA were to be repealed or dramatically changed by the US Congress or Supreme Court, the need to expand health insurance coverage to find ways to make health care affordable and to improve the health status of Americans and the performance of health care systems remain compelling incentives for change. In the absence of ACA, the mantle of reform could be picked

up by states and by insurance companies. The performance of other countries in providing health care and health insurance (Table 1) should serve as reference points in ongoing efforts to reform the US system.

Implications for Advocacy

Organizations that are committed to children and youth with special health care needs and disabilities (CYSHCN) must provide leadership in monitoring the status of ACA. If ACA law survives congressional challenges and Supreme Court rulings, regulations must be formulated, implemented, and evaluated. If ACA is altered, the new law must be evaluated and its regulations monitored. It is critical that the advocacy efforts are coordinated into a single united force because a large group garners more political power than many small and fragmented efforts. A coalition that includes the American Academy of Pediatrics, the Association of University Centers on Disabilities, Family Voices, professional societies, and condition-specific advocacy organizations should all come together to advocate for children and for CYSHCN.

Table 5. Comparison Between the Concepts of "Health Homes" in Affordable Care Act and "Medical Homes" Advocated Through the American Academy of Pediatrics

	Health Homes	Medical Homes
Patient population	Medicaid populations with specific conditions, especially mental health and substance abuse	Children and CYSHCN
Providers	Physicians or group practices; rural or community health centers; community mental health centers; home health agencies; and/or behavioral health service agencies	Physicians or group practices with primary care physicians as team coordinators
Design	May be located in 1 office or may be coordinated virtually	Generally located within a single primary care practice
Activities	Linkages to community and social supports to support individuals	Focus on child's health care and family

CYSHCN, children and youth with special health care needs and disabilities.

One pressing focus for advocacy in 2015 is the status of Children's Health Insurance Plan (CHIP). It is critical that Congress extend CHIP funding to 2019. One reason is that CHIP has had a good track record of enrolling children and providing them with health insurance. More importantly, without CHIP, as much as 56% of low-income families who qualify for CHIP may not be able to receive federal subsidies on health insurance exchanges. A problem in the law (the so-called ACA family glitch) is the provision that anyone who is offered affordable insurance (defined as <math><9.5\%</math> of income) from their employer is not eligible for federal tax credits; there is no limit on what the worker must contribute for family coverage, which is typically 2 to 3 times greater than individual coverage. If the worker cannot afford employer-based premiums for family coverage, then the children must rely on either Medicaid or CHIP and may be left without coverage if CHIP is unfunded.⁴¹

Affordable Care Act gives states and their payers considerable autonomy and discretion in implementation. Therefore, advocacy efforts will require state-by-state monitoring of policies in terms of their impact on children and CYSHCN.⁴¹ Cheng et al⁴¹ have provided a useful and systematic checklist of advocacy issues that begins with insurance availability and progresses to enrollment, benefits, availability of primary care and subspecialty providers to the delivery of high quality care. They also provide possible solutions for limitations in universal coverage, affordability, and multiple aspects of quality of care. This checklist is a valuable tool for the long-term advocacy efforts of the advocacy coalitions.

Many of the system reforms in ACA, such as ACOs and Health Homes, are likely to go forward regardless of the status of ACA because of their potential to improve quality and to control costs. Advocates must monitor the modification of models built for adult patients to fit the distinctive needs of children and CYSHCN.⁸ For example, child-relevant quality indicators need to be established and different models of care coordination implemented. It is important that institutional care in long-term care facilities be handled in the same system as home- and community-based care and not carved out into separate systems to avoid any diversion of individuals into institutional settings outside the scope of the law.

Paramount for these advocacy efforts is that the primary goal should be to improve health outcomes and not to reduce costs. Centers for Medicare and Medicaid Services is required under ACA to fund projects that demonstrate substantial cost savings to Medicaid within 6 months to 3 years. It is unrealistic to expect substantial and immediate cost savings in the care of CYSHCN because children overall, and even CYSHCN, are relatively healthy, use far less health care than adults, and account for a very small proportion of health care expenditures. It will be extremely challenging to achieve major cost reductions on predominantly low-cost services. Moreover, innovations in child health service delivery are likely to take much longer to achieve cost reduction,

even when such savings are possible. Reducing costs by cutting services to children will likely have a negative impact on their health and well-being during childhood, which would have lasting repercussions into adult life.⁵⁵⁻⁵⁷ Advocacy efforts need to emphasize that improving children's health care should be conceptualized as an investment and not simply a cost. In addition, the benefits of reform, including cost savings, must be evaluated in other sectors of government beyond health care, such as education or juvenile justice.⁴⁷

Implications of Affordable Care Act for Developmental-Behavioral Pediatrics

The interdisciplinary team that comprises developmental-behavioral pediatrics (DBP), including the physicians, psychologists, nurses, and therapists, must prepare for a new era of health care insurance and for new delivery systems. We recommend that the Society for Developmental and Behavioral Pediatrics (SDBP) establish mechanisms for monitoring ACA and for collaborating with the broad advocacy coalition regarding health care for CYSHCN. One option is to charge the Advocacy Committee of SDBP with these responsibilities. The Advocacy Committee then reports to the Board of Directors and the President of the Society who keep the membership informed. Of the many issues that the Advocacy Committee might focus on, we recommend close monitoring of the definitions of essential benefits in the federal exchanges and at the state level. It is critical that insurance plans cover the habilitative and rehabilitative services, mental health, and substance use disorder services, including behavioral health treatments, wellness, and chronic disease management that the DBP team prescribes routinely for CYSHCN.

The field must also monitor system reform efforts, including the design and implementation of ACOs and Health Homes. Primary care physicians will have a pivotal role within any reformed system. Therefore, it is important that DBP develop collaborative models with primary care. Around the country, there are many examples of DBP-primary care collaborations, including colocating DBP within primary care, using telehealth for onsite consultation, and creating explicit models of shared management. These efforts require a thoughtful evaluation of process and outcome. The timing and extent of subspecialty evaluation, particularly interdisciplinary practices, should also be evaluated to demonstrate value.

In an era of cost-consciousness, the field of DBP must organize health services research projects that verify its positive contributions to child and family outcomes for CYSHCN. The Practice Issues Committee of SDBP could be charged with monitoring systems reform efforts and communicating them to the membership. Research networks can also play a pivotal role in planning, conducting, and disseminating health services research regarding the role of DBP in the care of CYSHCN. DBPNet is an example of a subspecialty research network, currently comprised 14 academic health centers that treat patients

and train developmental-behavioral fellows.⁵⁸ DBPNet is documenting practice patterns within the network and investigating the use of outcome measures for selected patient groups. Important next steps for the network are to evaluate models of health care delivery for CYSHCN and to expand the identification of outcome measures that can be used for assessments of quality beyond any single diagnostic category to the group of CYSHCN.

CONCLUSIONS

Affordable Care Act (ACA) is an important US law that is pushing reform in health care delivery and health insurance with the simultaneous goals of (1) decreasing the number of uninsured Americans, (2) making health insurance and health care affordable, and (3) improving health outcomes and performance of the health care system. The law was not conceptualized with children in mind and yet will have a major impact on children and youth with special health care needs and disabilities (CYSHCN). CYSHCN need health insurance to meet their health care needs. On balance, we are optimistic that the law will improve health care insurance coverage, affordability, and adequacy for CYSHCN. However, important challenges remain, including the limitations of grandfathered plans, the possible elimination of the CHIP program, the nature of ACOs for children, and the application of Health Homes for CYSHCN. It is important to learn about the laws, track regulations that are developed, and assess the direction of change. Going forward, advocacy on behalf of CYSHCN must assure that they benefit from the legislation and specifically that the proportion of children with insurance does not decline. Systems reforms must be developed and tested for CYSHCN. The goal of cost reduction must not trump improvements in care. The interdisciplinary members of developmental-behavioral pediatrics (DBP) practice must quickly assert the role of DBP within the new health care delivery system, documenting that our evaluations and treatments make a measurable improvement in the health of CYSHCN and their families and assuring that we have a place at the table when health care reform is discussed.

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