

HEALTH POLICY CASE STUDY

DECEMBER 2012

A SHIFTING HEALTH LANDSCAPE FOR ADOLESCENTS AND YOUNG ADULTS: PLANNING FOR THE IMPLEMENTATION OF FEDERAL HEALTH CARE REFORM IN NEW YORK



University of California
San Francisco



We Understand • We Care • We're Here for You



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Commissioned by Mount Sinai Adolescent Health Center

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THE MOUNT SINAI ADOLESCENT HEALTH CENTER: SETTING THE STAGE FOR THE CURRENT REPORT

Since 1968, the Mount Sinai Adolescent Health Center (MSAHC) has been addressing the health needs of young people (aged 10-24) across New York City and beyond. MSAHC aims to ensure that the health needs of adolescents and young adults are addressed in the most comprehensive manner, taking into account the mosaic of diverse public and private health care financing systems currently supporting the delivery of care. Uninsured youth are seen for free. Thus, as significant national and state-level efforts to expand and enhance health care access, coverage, and reimbursement mechanisms are being implemented, MSAHC leadership commissioned an independent evaluation of MSAHC for two purposes: (1) to determine the effectiveness and appropriateness of their adolescent-centered, holistic, confidential health service delivery model; and (2) to explore how federal and state policy issues affect service delivery and the financing of care for young people. This study is also aligned with the Institute of Medicine's (IOM) report, *Adolescent Health Services: Missing Opportunities*¹, which called for more research on how health care settings, systems, and policies help to promote high quality health services for adolescents, as well as barriers they encounter in the provision of such services.

ICF International (hereafter ICF) was selected to conduct the evaluation of MSAHC. The evaluation has 3 components: (1) a 4 year quantitative outcomes study comparing adolescents and young adults enrolled in MSAHC services with similar adolescents drawn from the surrounding community who are not receiving MSAHC services; (2) a qualitative component consisting of interviews and focus groups with MSAHC patients and providers; and (3) a health policy component to focus on in-depth analyses of public policy issues as they relate specifically to the MSAHC and adolescent health care delivery in general.

ICF's overall evaluation will include a baseline and final evaluation report, to be released in October 2015. To study the evaluation's health policy component, ICF partnered with the Philip R. Lee Institute for Health Policy Studies and the Department of Pediatrics, Division of Adolescent and Young Adult Medicine at the University of California, San Francisco (hereafter UCSF). Thus far, UCSF has published the first Health Policy Update: *Financing Health Care Services at Mount Sinai Adolescent Health Center: Overview of Findings from 2010*, which analyzed issues pertaining to the financing of adolescent health care services at MSAHC through quantitative analysis of clinic financial data.

The current study, *A Shifting Health Landscape for Adolescents and Young Adults: Planning for the Implementation of Federal Health Care Reform in New York*, is the second in a series of health policy publications. The goal of this study is to focus attention on the extent to which the health care needs of adolescents and young adults are being planned for and addressed as New York implements the Patient Protection and Affordable Care Act (ACA) and other health service delivery reforms. As MSAHC serves as a national model for other adolescent-targeted health care providers, who share similarly in the opportunities and challenges of implementing health care reforms, we hope that this report's focus will help inform providers and program administrators facing this new and rapidly changing landscape. In turn, this is anticipated to help health care systems better meet the needs of the adolescent and young adult populations they serve. Future policy analyses include a new update pertaining to the financing of MSAHC, as well as additional case studies reflecting key and emerging health policy-related topics.

MSAHC is grateful to Atlantic Philanthropies for their support of this research.

¹ IOM (Institute of Medicine). *Adolescent Health Services: Missing Opportunities*. Washington, DC: The National Academies Press; 2008.

INTRODUCTION

In 2010, Congress enacted the Patient Protection and Affordable Care Act (ACA) to increase the number of individuals in the United States with health insurance and to decrease the cost of health care. With the Supreme Court's landmark decision on June 28, 2012, the constitutionality of key provisions of the ACA were upheld, including the individual mandate (which requires most individuals and their dependents to maintain "minimal essential" health insurance coverage) and the expansion of Medicaid eligibility.¹ While the Supreme Court settled many important issues in regards to ACA, the health policy landscape of Federal health care reform continues to be shifting. Thus, the purpose of this Health Policy Case Study is to better understand the extent to which planning efforts in New York State are considering and responding to the critical health needs of adolescents and young adults as the state actively pursues implementation of the ACA.

New York State was selected as the focus of this report because it has played an important pioneering and leadership role in addressing the health needs of adolescents, young adults, and traditionally underserved populations. Historically, it has also been a state of immigrants and the manner in which immigrants will and will not be eligible is a special challenge with regards to health care reform efforts. This case study provides a descriptive "snapshot" of how a sample of key experts on adolescent and young adult health care and health care policy in New York State are responding to a myriad of health care reform-related policy decisions and planning efforts. The intent of these findings is to provide insights on ACA implementation for health care systems, such as New York City's Mount Sinai Adolescent Health Center (MSAHC), that play a critical role in the provision of health services to adolescents and young adults. This comprehensive health program for young people, along with a number of other entities, will need to prioritize their efforts as systems of health care delivery and financing undergo major changes in the years to come.

In the following sections, we present a brief overview of the ACA with particular focus on adolescents and young adults, as well as the interview methodology used in conducting interviews for this brief. Results are then presented according to key themes that emerged across interviews. We conclude the case study with an overarching summary and implications with a specific focus on the health needs of adolescents and young adults in light of the historic environment in which these efforts are unfolding.

BRIEF OVERVIEW OF THE FEDERAL PATIENT PROTECTION AND AFFORDABLE CARE ACT AND INSURANCE COVERAGE FOR ADOLESCENTS AND YOUNG ADULTS

The two primary aims of the ACA are to increase the number of Americans with health insurance and decrease the cost of health care. Young adults play a particularly important role in the health insurance market place. When young adults have insurance, it not only benefits the individual, but there are also benefits to the entire health system.² As young adults are relatively healthy, health insurance companies can collect health premium income from this population with relatively little risk of having to pay for major health care services. Thus, young adults contribute to a broader insurance pool comprised of healthier individuals which helps to defray the costs of health care over many more “covered lives.”

Prior to the ACA, young adults were more likely than any other age group to be uninsured. Approximately one-third of this nation’s uninsured are young people in the age group of 19-26 year olds.³ Young adults tend to earn less money than older adults which makes it difficult for them to buy insurance on their own. They are also less likely to be offered employer-based coverage due to the nature of their jobs. In addition, because young adults are generally healthy, they often feel that they do not need health insurance or consider health insurance to be a lower priority than other more immediate financial concerns.³ They may not anticipate the risks and consequences of having a major health issue while uninsured or of foregoing preventive care, placing a higher importance on the desire to avoid the cost of insurance.⁴

On June 28, 2012, the U.S. Supreme Court upheld the constitutionality of the ACA,¹ thereby allowing many of its provisions that are beneficial for adolescents and young adults to remain in effect. The ACA contains a number of significant components that are aimed at promoting the health of adolescents and young adults.⁴ First, the ACA requires health plans to expand dependent coverage of young adults, up to age 26, on their parent’s health plan. This has already significantly increased the number of young adults now receiving health insurance coverage. Recent estimates indicate that this component of the ACA has expanded coverage to approximately 6.6 million 19–25 year olds who otherwise would have lacked health insurance if not for the ACA.⁵ It also provides stronger protections for students and dependents insured through college and university health plans.⁴ Second, the ACA expands coverage for low-income

individuals living under 133% of the Federal poverty level (FPL)ⁱⁱ through changes to eligibility criteria for the Medicaid program. However, based upon the Supreme Court decision, states will still have the opportunity to determine if they will participate in the Medicaid expansion,¹ thus likely impacting many low income young adults. Third, the ACA requires the establishment of Health Benefit Exchanges at the state level. Health Benefit Exchanges are structured marketplaces that allow a range of health insurance plans to be purchased by small employers and individual purchasers (see section on Exchanges for additional information). Fourth, the ACA allows documented immigrants to purchase coverage through the Exchange; although undocumented immigrants are not eligible for ACA coverage. Fifth, the ACA requires health plans to provide preventive health services without cost sharing—a potentially significant benefit for adolescents and young adults. This includes, but is not limited to, expanded maternity care services for dependents and contraceptive access without cost sharing—all of which are extremely important for adolescents and young adults. Insurance policies must cover these and a number of other “essential” health benefits in order to be able to participate as part of the Health Insurance Exchanges. Furthermore, all Medicaid state plans must also cover these services by 2014.⁶

Interviews for this case study began prior to the Supreme Court’s ruling when there was a great deal of uncertainty about the fate of Federal health care reform efforts. Since the initial passage of the ACA in March 2010, states have faced a difficult dilemma as to whether or not they should proceed with implementation efforts in anticipation of a ruling that would or would not preserve the ACA as a whole or possibly eliminate critical components.⁷ Noteworthy, and in relation to young adult coverage, three major health insurers decided, prior to the Supreme Court ruling, to preserve the provision in ACA that allows young adults to remain on their parent’s health insurance policies until aged 26.⁸ In addition, states, like New York, that began planning efforts or actual implementation prior to the court ruling, are now in a better position to comply with the provisions and timeline specified under the Federal legislation than those who waited for the court’s ruling. However, even with the Court’s decision, states will still have decisions to make regarding whether and how to implement an Exchange and whether or not to comply with the Medicaid expansion. In the themes presented within the case study below, we provide additional details on each of the aforementioned aspects of the ACA.

ⁱⁱ FPL for a single individual living in New York is \$11,170/year: <http://aspe.hhs.gov/poverty/12poverty.shtml/>

METHODOLOGY

A total of 29 health care administrators, health policy researchers, adolescent health providers, and advocates were identified as experts in the field and key informants to be interviewed for this study. Selection of study participants was a two-step process. First, as part of the external evaluation of the MSAHC, we sought the assistance of MSAHC leadership in identifying potential stakeholders to participate in this study. Addressing the health needs of young people, aged 10–24 years, across New York City since 1968, MSAHC's insights regarding key individuals actively engaged in the planning, development, and implementation of health care reform in New York were valuable to the selection process. Second, additional participants were recruited from the New York Health Care Reform Advisory Board, while others were invited based on their health care and policy expertise. Recruitment of participants occurred through a formal, personalized letter from UCSF inviting the key informant to participate in an interview. Two to four telephone, email, and fax attempts were made to follow up and engage those participants who did not immediately respond to the invitation.

Of the 29 stakeholders identified to participate, 14 completed the telephone interview (which took between 30–60 minutes). Reasons for declining to participate included the following: seven stated they were not sufficiently versed in the topic of health care reform or stated they could not comment on its potential impact on adolescents; five did not respond to our attempts to contact them after a maximum of four attempts; two stated they did not have enough time to complete the interview, and one started the interview, but did not complete it because he or she felt unable to comment on the potential impacts of a law that was currently in flux. The types of roles and responsibilities of the individuals who declined to participate are similar to those who participated in the study. Analyses of all the successfully completed interview responses, as well as the primary themes that emerged, were found to be relatively consistent and of sufficient thoroughness that they provide a rich source of information to draw upon for this case study.

Participants were asked several open ended-questions about health care reform in New York in light of the ACA. Specifically, they were asked about how the Health Benefit Exchange in New York was being designed; the extent to which insurance plans are taking into account the special health needs of young people; the enrollment process and strategies to maximize enrollment; how confidentiality for young people will be dealt with under the ACA expansions; plans and implications for adolescents and young adults, including those from immigrant backgrounds; and the potential benefits

and challenges of the ACA for New York's adolescents and young adults. These questions were developed through a literature review related to issues of implementing the ACA and discussions with health leaders from MSAHC and the evaluation team (ICF and UCSF) to ensure inclusion of most relevant topics. After obtaining informed verbal consent, each interview was audio recorded and transcribed. Data were stored in a secure, password-protected computer.

Each transcript was analyzed to identify key themes that were discussed (using pre-set categories generated from the interview guide), as well as to identify new themes that emerged from the interviews. Data were then further analyzed to identify the range of responses in each theme, the relative importance of different themes, and divergent/convergent responses within each theme. This study received approval from the Institutional Review Board (IRB) at the University of California, San Francisco.

The following results section presents findings reflecting the major ACA-related themes, including (I) Health Benefit Exchanges; (II) Medicaid expansion (III) Basic Health Plan; (IV) the Catastrophic Coverage option; (V) enrollment and health care access; (VI) special issues for adolescents and young adults; and (VII) closing reflections of the participants. Within each section, a brief overview and background of each theme is provided, followed by comments from the study participants. The case study concludes (section VIII) with a number of implications for consideration in planning and implementing health care reform efforts that support the health of adolescents and young adults.

RESULTS

I. Health Benefit Exchanges

Background: The ACA requires the creation of state-based Health Benefit Exchanges (hereafter called “Exchanges”), through which individuals can purchase coverage, with subsidies in the form of premium and cost sharing credits for individuals/families with incomes between 133–400% of the FPL, as well as providing small businesses with the same opportunity to purchase coverage.⁹ The intent is to offer a choice of health insurance plans that operate on the same set of regulations and pricing structures as those offered to individuals within larger employer-based private markets.¹⁰

Small businesses will also receive a tax credit to purchase employee health insurance through the Exchanges.¹¹ The Exchanges are intended to provide consumers with a more affordable alternative to the more expensive private health insurance market. The U.S. Department of Health and Human Services (HHS) will evaluate if states are willing and able to implement the Exchange by January 1, 2014, or as an alternative, establish a partnership with the Federal Government in establishing a Federally Facilitated Exchange (ACA section 1322b). By January 1, 2014, the Exchange must be fully operational (ACA section 1211b).¹² In addition, states may allow more than one Exchange to operate, as long as each Exchange serves a distinct geographic area. For states that opt out of a state-based Exchange, the Federal Government will assume responsibility for the Exchange. As a result of the cost sharing and subsidies offered under the state-based Exchange, it is estimated that across the nation 4.9 million low-income young adults (aged 19–29 years) with incomes between 133% and 400% FPL will qualify for coverage in 2014.⁴

In January 2012, when the interviews for this study began, New York lacked the necessary legislation to establish a state-based Exchange and many of the interviewees considered this a “road block”. At the same time, one informant, Lorraine Gonzalez, LCSW acknowledged, “The New York State Department of Health is very vested in moving forward”. Many participants commented that New York State has been a leader in health care initiatives aimed at supporting the health care needs of low income youth and were hopeful that New York would continue to be a leader in any future health care reform initiatives.

“New York has always prioritized access to health care for children and adolescents, evidenced by its robust Medicaid program for children and the expansion of our Child Health Plus program to families under 400% of the Federal poverty level.”

Anthony Fiori, MPA

A few participants indicated that the state was moving forward as if it were establishing an Exchange because Governor Cuomo included funding relief in the 2012–2013 state budget for local Medicaid expenses. This was an attempt to garner statewide savings, while moving forward with health reforms proposed at the state and Federal level.¹³ As one participant stated:

“The governor put monies in his budget for 2012–2013, anticipating challenges to the passage of exchange legislation.”

Alice Berger, RN, MPH

On April 12, 2012, New York’s Governor Cuomo issued an Executive Order to establish the state’s Exchange in an effort to expedite New York’s ability to “carry out the requirements and serve the goals of the ACA”.¹⁴ While the Executive Order resolved the overarching issue of establishing an Exchange, interviews yielded additional concerns regarding its development and implementation, and the potential impact of an Exchange on New York. Interviews revealed five main concerns: (1) insufficient time to create and implement an Exchange that meets the diversity of needs in New York; (2) uncertainty about the role of counties; (3) concerns about affordability; (4) potential confusion around multiplicity of insurance plans; and (5) concerns about ensuring the quality of health care services.

1. Concerns about an insufficient amount of time to create and implement the Exchange

The complexity of establishing a new state entity within a relatively short period of time, as well as creating the necessary infrastructure to assure maximum enrollment, was noted in many of the interviews. Most expressed concern that New York is under significant time pressure to create and implement an Exchange that would adequately meet the diverse needs of their state.

“This is a very big challenge with very little time.”

David Sandman, PhD

“In New York, there is so much diversity and uniqueness to take into account when designing the Exchange. We really should be customizing it ourselves and planning quickly.”

Lorraine Gonzalez, LCSW

“The New York State Department of Health is on an accelerated deadline that will require tremendous collaboration and infrastructure changes.”

Alice Berger, RN, MPH

“There is a concern about the pace of getting the authority to move forward because of the tight timelines on the Federal side... they need to be certified in less than a year and taking applications in two years. The biggest concern is the timing.”

Kate Breslin, MPH, MCRP

Thus, even with New York’s preplanning efforts, there is considerable work that needs to be done within a relatively short amount of time to comply with the timeline specified in the ACA.

2. The role of counties in the Exchange

Interview participants expressed some concern and uncertainty about the role that counties will play in the development and implementation of the Exchange. On the one hand, interviewees felt counties have a better sense than the state of how to implement the Exchange at the local level. Reflecting the perspective of several interviewees, there is an important role for local, in-person assistance.

“Counties presently play a strong role in the Medicaid eligibility process and counties pay for a share of the program.”

Kate Breslin, MPH, MCRP

On the other hand, there was concern about the county variation in enrollment that exists in the Medicaid program.

“Even though many of the rules are made statewide and set by Federal law, there remains a large variation from county to county.”

Bridget Walsh

Since the time of the interviews, the role of counties has been further clarified. In New York, counties will be represented on the Exchange advisory committees, but there is no plan to implement a decentralized Exchange model through 58 counties. Similar to nationally-established policy, the Exchange will operate centrally in states (or regions),

but with application assistors and others providing localized support to assure successful enrollment of those individuals applying for coverage and navigating new systems of health insurance coverage.

3. Concerns about affordability of health insurance

A study by the Commonwealth Fund analyzed the affordability of health insurance with regards to an individual's income. This study found that more than 10 percent of low-income individuals with incomes two to three times the FPL will be unable to afford the high out-of-pocket costs of purchasing health insurance through state Exchanges, without reducing spending on other necessities.¹⁵ This perspective was reflected in several of the interviews.

"I am concerned it will not be affordable for teens and young adults and could lead to an increased number of uninsured."

Deborah Kaplan, PA, MPH

Overall, study participants felt that while the intent of the ACA is to make low cost coverage more widely available to families and individuals, there is wide-spread concern that cost will remain an important barrier-especially for young adults.

4. Potential confusion around multiplicity of insurance plans

Participants expressed some concern about the potential for confusion around the multiple insurance options created within the Exchange that include the bronze, silver, gold, and platinum tiers, as well as the option for catastrophic coverage, each with varying out-of-pocket costs and benefits for enrollees. While participants acknowledged the importance of providing consumers with multiple options, they also expressed concern that too many choices may be overwhelming for the public. As one of the interviewees stated:

"If insurers flood the Exchange with 1,000 different products, it provides no choice to somebody when there are too many choices."

M. Tracey Brooks, Esq.

5. Concerns about ensuring the quality of health care services

There was also some discussion about how to ensure that health plans maintain minimum health care quality standards in health care reform efforts. Section 1311 of the ACA requires health plans to obtain certification as a Qualified Health Plan (QHP) from a national entity, such as the National Committee of Quality Assurance (NCQA), in order to participate in the Exchange.¹⁶ Whether or not this system will be sufficiently

rigorous to assure consumers and advocates that quality of care standards are being met will continue to unfold as additional details and information are made available. Furthermore, as quality metrics are established and implemented, careful monitoring of the quality of care received by young people, as well as consumers in general, will need to be carefully monitored both at the Federal and state level. Despite these challenges and concerns, it should be noted that New York has measured and reported on health care quality for public and commercial plans over the past decade through their Quality Assurance Reporting Requirements (QARR) program.¹⁷ This effort places New York ahead of most other states¹⁸ in terms of tracking and reporting on health quality performance measures.

As the details of benefit packages become more specified, the special considerations for adolescent and young adult health care needs will need to be considered. Evidence-based adolescent and young adult preventive health services have the potential to reduce morbidity and mortality while enhancing health promotion.¹⁹ The ACA already requires that evidence-based preventive health guidelines for adolescents and young adults be incorporated in the delivery of health care. These include guidelines established by the U.S. Preventive Health Services Task Force²⁰, Bright Futures²¹, the immunization guidelines from the Centers for Disease Control and Prevention,²² and the Institute of Medicines recommendations for women's health that are to be provided without cost-sharing.²³ The delivery and integration of these preventive services will be critical. Adolescent health clinics (such as MSAHC and school-based health centers), as well as family planning and other community-based clinics, have demonstrated ways of delivering comprehensive, integrated care in a confidential manner and can serve as models for health care reform efforts.

II. Medicaid Expansion

Background: Prior to the ACA, there was considerable variation in Medicaid eligibility. Eligibility varied from state to state and according to the age of the child and family income. In addition, many states did not provide Medicaid to low-income adults without children unless they were disabled or elderly.²⁴ By 2014, the ACA's Medicaid expansion will require state programs to be more standardized across the country and will also enable low income adults (aged 19–65 years) with or without children to be eligible to enroll in Medicaid if their income levels are below 133% FPL. However, while the U.S. Supreme Court upheld the constitutionality of the ACA's Medicaid expansion, it eliminated the provision that would have penalized states for not implementing the expansion by withdrawing all of their Medicaid funds.¹ Thus in practice, states do not have to expand Medicaid to 133% FPL. If states opt to expand Medicaid, the ACA

increases Federal funding to cover all of the states' initial expansion costs in 2014 through 2016, and gradually decreasing to 90% in 2020.²⁵

New York, with its long history of providing health coverage to its low income population, has opted to comply with the ACA's Medicaid expansion requirements. New York is one of only a small number of states that, even prior to the ACA, offers health coverage for adults without children and provides expanded coverage to parents through New York's Family Health Plus (FHP).²⁶ In brief, FHP is a Medicaid expansion program for adults aged 19–64 who do not have health insurance but whose incomes are too high to qualify for Medicaid. It is funded by Medicaid and is part of New York's Section 1115 Partnership Plan waiver.^{26,27} As a result, when compared to other states, New York possesses a smaller proportion of adults who will become "newly eligible" for Medicaid under the ACA. Yet at the same time, the ACA's Medicaid Expansion program will allow New York to capture Federal funding for the population they already serve. The ACA requires that the newly eligible population receive "benchmark benefits" which may not be as extensive as current Medicaid coverage, but which must be at least equivalent to the "essential health benefits" that are being planned for through the New York Exchange.²⁸

Populations traditionally covered under the Medicaid program, such as low income children and pregnant women, will continue to be eligible to receive Medicaid Standard benefits.²⁹ In New York, children are eligible for public health insurance with family incomes up to 400% of the FPL.²⁸ They are eligible for Medicaid up to 133% of the FPL and the State's Children's Health Insurance Program (CHIP) if they are 133-400% of the FPL. Prior to the ACA, families with incomes over 400% could purchase CHIP at full cost. Under the ACA, children who are unable to enroll in CHIP because their income exceeds the maximum 400% FPL will be eligible for tax credits in the state Exchanges.³⁰ Pregnant women are eligible for public health insurance up to 200% FPL and can be enrolled in both Medicaid and CHIP.^{29,30}

"New York has extremely generous health care coverage for young people and adolescents. One could almost argue that New York has 'universally available coverage' with high and generous Medicaid eligibility levels, in addition to New York's Child Health Plus program, which is the most generous CHIP program in the nation."

David Sandman, PhD

In light of New York's existing health care subsidy and 2011 legislation that requires all Medicaid recipients be transitioned into managed care plans,³¹ New York is well

positioned to expand coverage to the additional newly-eligible population through the ACA. At the same time, study participants expressed concerns about ensuring the continuity of coverage, especially for low-income individuals who face income fluctuations that could cause them to move between different types of health insurance coverage (e.g., a private Exchange-based plan or a public coverage program, such as Medicaid, depending upon income eligibility requirements).

“Churning’: individuals being enrolled, disenrolled for one reason or another, and then enrolled again is a problem. We need to keep people within the system if they need to, rather than falling out and getting back in.”

Richard E. Kreipe, MD

“People are going to be moving back and forth over this eligibility line with great frequency due to changes in income and family circumstances. We need to do everything we can to ensure that they do not fall between the cracks and that they maintain their coverage.”

David Sandman, PhD

Thus, not surprisingly, participants felt strongly that health care reform planning efforts need to make the system as seamless as possible with regards to fluctuations in individual and family income eligibility.

III. Basic Health Plan

Background: Under the ACA, states have an option to create a Basic Health Plan (BHP) to provide coverage for low income individuals with incomes 133–200% of the FPL.³² This option is designed to help this low income group, which is commonly uninsured because their incomes are more than 133% of the FPL, including certain legal immigrants who are ineligible for the Medicaid program (e.g. because they were granted status as lawful residents within the past five years). The BHP option would benefit individuals whose insurance status depends on the cost of available coverage (e.g., those who experience fluctuations in their income, which affects their eligibility for coverage). This plan would be run by the state through direct contracts with health plans or providers,³³ but financed by the Federal government, which allows states to utilize 95% of what the Federal government would have provided to these individuals to purchase coverage on their own through the state-based Exchanges.¹⁶ Although individuals in the BHP would not be eligible to participate in the Exchange,³² the BHP must adhere to the minimum benefits that ACA requires at a cost that does not exceed what the individual would have to pay through the Exchange. The aim of the BHP is to

offer consumers lower premiums and copayments than insurance plans sold through the Exchanges.^{32,33}

Despite the aim of the BHP to provide affordable coverage to low-income individuals, policy experts have raised some concern that a BHP could reduce the number of people enrolled in the Exchange, thereby decreasing the number of participants sharing the administrative and other coverage cost burdens. As a result, this would likely increase the cost for individuals buying into the Exchange.³³

States have the potential to save money if they set insurance premiums in the BHP lower than Exchange rates.³⁴ Approximately half of those interviewed discussed the financial benefits of a BHP, often referring to a report by the Community Service Society of New York (CSSNY).³⁵ This report analyzed the financial benefits of a BHP to New York and estimated that the state would receive roughly \$3.4 billion in Federal financing to go towards New York's BHP, based upon New York's current Medicaid expansion program, FHP.³⁵ Based on the current costs of FHP, the Federal financing, and the anticipated increase in the number of those enrolled, a BHP would at least initially yield a cost neutral effect for New York.³⁵ New York would potentially save money in a BHP largely because the program would provide Federal funds to cover legal immigrants living in New York who currently are covered through the state-funded Medicaid program.³⁵ If New York adopted a slight increase in enrollee cost-sharing, it could yield an anticipated net financial gain to the state of around \$954 million annually.³⁵ Many of the interviewees expressed uncertainty around the implementation of BHPs; however, they emphasized the potential financial benefits of the BHP to the state given the eligibility profile of its population.

"If implemented, a BHP would provide an affordable option for coverage and it would be in the interest of the state to pursue it... Financially, it's a good move."

Lorraine Gonzalez, LCSW

"If structured appropriately, a [BHP] could provide tremendous fiscal relief to New York State."

David Sandman, PhD

Two participants articulated the benefits a BHP would have on low-income populations by providing them with an affordable health insurance option, as expressed in the following statement:

“Clearly, a BHP could provide many significant benefits to New York’s consumers. It would vastly increase the affordability of insurance for low-income people in the state.”

David Sandman, PhD

With regards to adolescents and young adults, any BHP needs to consider and include the range of recommended, evidence-based preventive health services with adequate visit time and reimbursement mechanisms for providers. It also needs to allow for the full integration of behavioral and health services.

IV. Catastrophic Coverage

Background: As mentioned previously, the ACA requires the offering of a separate catastrophic plan option. The catastrophic plan is available only in the individual market for individuals under the age of 30 or to those who are exempt from the mandate to have coverage because available coverage is unaffordable or enrollment in available coverage would be a hardship (i.e., if the lowest cost premium exceeds 8% of their income¹¹). In brief, catastrophic coverage provides protection in the event of an expensive (catastrophic) illness. It also exempts preventive benefits and up to three primary care visits from the deductible for individuals with catastrophic coverage. However, other health care services are subject to higher out-of-pocket costs.¹¹ The most significant concern about catastrophic coverage is its potential unintended consequence on the young adult population. Participants worry that it may be considered an attractive option because of its relatively low premium cost and as a consequence would limit such individuals’ access to comprehensive health services.

“We’re concerned that catastrophic plans will be marketed at young adults without explaining the limited coverage the plans provide. Some young people who could use subsidies to purchase a high quality plan may buy a catastrophic plan only to realize it covers just three doctor visits before the deductible is reached. These plans could discourage the excitement around previously uninsured young adults being able to purchase coverage on their own for the first time. There are also potentially negative long-term health implications for people with high-deductible plans, in that it could restrict their health care access.”

Rory O’Sullivan, JD, MPP

Another participant noted that Catastrophic Coverage could present a challenge to many young adults and felt there was an alternative to these plans.

“I would prefer to see the creation of a BHP [vs. a Catastrophic Care option] so young people can access the comprehensive health insurance coverage they need. Those who advocate for consumer rights are pushing for the basic health plans to be included.”

M. Tracey Brooks, Esq.

In sum, some participants felt that the inclusion of the Catastrophic Coverage option raised particular concerns for the young adult population and would not provide them with the continuity of care that adolescents and young adults need. However, there is no research on how young adults currently choose insurance or health plans. Similar to other populations that may have inadequate information regarding their eligibility, adolescents and young adults will likely need outreach and support in order to make informed choices that best suit their needs. Current programs (e.g., family planning clinics, school-based health centers, and other community-based programs) that are already geared to serving this population may be particularly important entry points for both education about health plan options and enrollment, representing a single ‘portal of entry’ (see Section V).

V. Enrollment and Health Care Access

Background: Under ACA, states will be required to design, coordinate, and implement a technology-supported enrollment system to help uninsured individuals obtain insurance coverage. The law requires states to develop a “consumer-friendly” application process, support coordination across different options to enable seamless transitions, and reduce the burdens often associated with enrollment and renewal.³⁶ A key goal of the enrollment process under the ACA is to streamline the overall approach for determining eligibility and then to enroll consumers in the appropriate health plan and coverage options via telephone, mail, online, or in-person. The aim of the IT system, a critical component to facilitation of this process, is to maximize the reliance on technology to ensure continuity of coverage, while reducing the burden on the consumer.³⁶ It also aims to minimize the up-front information and documentation required to establish eligibility by tapping into data that is available from other sources.³⁷ New York’s efforts in this regard were significantly boosted when it was selected by HHS as one of seven “Early Innovator” states.³⁸ New York received a \$27.4-million grant to develop the necessary IT infrastructure for use in determining individual eligibility and enrollment procedures for the state-based Exchange.³⁸

In addition to the IT infrastructure, the ACA requires the incorporation of a Navigator Program. Navigators are individuals who have a relationship with or who are able to

form a relationship with both the insured and uninsured, thus, a useful strategy to facilitate enrollment among the people they work with most closely. The Navigators are assumed to be able to provide eligible enrollees with “fair, accurate, and impartial” information regarding coverage options.³⁹

While New York has benefitted from the initial Federal investment in developing their IT system, it is unclear how this “new system” will be integrated with procedures already established by the state. For instance, in 1998, as New York worked towards the expansion of subsidized insurance coverage for children, outreach and enrollment strategies were developed to meet the needs of consumers at the local level. Facilitated Enrollers were created to expand the accessibility and ease of applying for government-funded health insurance.⁴⁰ While the program was originally implemented to help increase the enrollment of children, it was later expanded to meet the needs of adults. Facilitated enrollment services are currently provided across 41 community-based organizations throughout New York.⁴⁰

Participants shared a common sentiment that the success of the ACA depends on the state’s ability to implement an effective enrollment and reenrollment process. They felt that uninsured populations will only benefit from the ACA if they are able to more easily access and enroll in health insurance plans. Therefore, the enrollment process needs to accommodate the needs of adolescents and young adults. A number of interviewees voiced concerns with how the enrollment process will be facilitated and simplified, while ensuring enrollment. Their concerns were categorized into three main themes: (1) the importance and challenge of creating a more “streamlined” and “simplified” process with a single portal of entry; (2) the importance of maintaining the role of the Facilitated Enroller, while implementing the new Navigator program; and (3) concern for individuals being eligible but not enrolled.

1. The importance and challenge of creating a more “streamlined” and “simplified” enrollment process

As noted previously, the ACA calls for a single streamlined form that all states will use to enroll individuals eligible for state-subsidized programs based on their income. Streamlined eligibility rules will likely make it easier for eligible New Yorkers to obtain and maintain their health care coverage. A Web-based portal is intended to allow a variety of databases to securely exchange and utilize data in order to determine an individual’s eligibility for the various health plans within the state-based Exchange.⁴¹ Six of the study participants emphasized the importance, as well as the challenges, of

implementing such a system, with overwhelming concern for ensuring enrollment in the Exchange whatever the pathway.

“There is a desire to streamline what is required from people and what they want people to bring in, and to ensure that enrollment works in the most efficient way to get people covered.”

Kate Breslin, MPH, MCRP

“Make enrollment easy. Facilitate enrollment. Keep enrollment going.”

Richard E. Kreipe, MD

“Exchanges should provide a wide variety of interfaces so that different populations have easy access. For example, a great way to reach young adults is to utilize mobile technology and text messaging.”

Rory O’Sullivan, JD, MPP

Participants also expressed awareness that many adolescents and young adults will not seek medical attention unless they feel that they have a health problem or concern and will forgo needed care if they have concerns about a lack of confidentiality. Several of those interviewed expressed the importance of having the network of adolescent health care providers, including family planning providers, integrated into the ‘single portal access’ system of care to connect adolescents and young adults to needed health coverage.

“We want to be able to give people the information they need to choose the program best suited for them and the coverage they desire. It makes great sense for adolescent health care providers to be part of that system, since often times they are the only health care they seek, making them the direct point of entry.”

M. Tracey Brooks, Esq.

“By combining enrollment assistance with the actual provision of services (i.e., within a health center), it enables clients and young people in particular, to obtain their health care at the same site where they are obtaining insurance coverage.”

Alice Berger, RN, MPH

“Family planning providers are an important entry point to comprehensive care for teens.”

Deborah Kaplan, PA, MPH

2. Maintaining the role of the Facilitated Enroller, while incorporating the Navigator program

As noted above, one key aspect of the Navigator role, as defined by the ACA, is to increase public awareness about qualified health plans through public outreach and education, distribute “fair and impartial information” about tax credits and enrollment, and provide consumer support and referrals for all enrollees.⁴² A common theme expressed in the interviews was the importance of support or “face-to-face” interaction to educate and enroll clients in the appropriate health plan. Participants felt that the human contact was necessary to successfully reach out to and enroll individuals in the health insurance program for which they are best eligible. Five of the study participants commented on the importance of education and outreach to ensure the success of the Exchange.

“In order for [the Exchange] to be successful, local communities must be engaged in helping to craft the education and outreach message. We, as safety net providers, know well the concerns and reality of our client base and this must be reflected in the varied forms of educating and reaching all eligible populations.”

Alice Berger, RN, MPH

“It is clear that outreach and marketing must be central functions of the Exchange. Navigators will take on a sort of Ombudsman role to assist people throughout the entire process, beginning with initial plan enrollment and then with issues or problems that could emerge further down the line.”

David Sandman, PhD

Many participants were not entirely clear about how the Navigator program of the ACA would be integrated within or coordinated with New York’s established Facilitated Enrollment program. Half of the respondents identified the importance of combining the Navigator Program with the community-based Facilitated Enrollers. Three of these participants mentioned the possibility of the Facilitated Enroller being trained to become a Navigator. How either Facilitated Enrollers or Navigators would interact with adolescents and young adults was not described or detailed by any of the respondents.

“When it comes to the component of Navigators, we recommend a ‘hub and spokes model’, wherein you have a central hub on the back end, but still require the community inroads (spokes) to reach all populations. New York should not reinvent the wheel, but really leverage from existing resources within its facilitated enrollment system.”

Lorraine Gonzalez, LCSW

"We are hoping to build a system with the largest number of navigator-type locations so that more people have access to help and assistance. It is important that online registration still has the ability to have a face-to-face meeting for support as well."

M. Tracey Brooks, Esq.

3. Concern for individuals being eligible but not enrolled

Several participants voiced concern about special populations who would be eligible for health insurance coverage, but who might not be enrolled. A few participants noted the extensive enrollment problems for existing public health insurance programs, such as Medicaid and CHIP. It is widely recognized that many individuals who are eligible for health programs, such as Medicaid, are not currently enrolled for a variety of factors including lack of information, concerns about the stigma associated with enrollment, and other related concerns. Thus, there is concern that these types of barriers will "spill-over" into the ACA implementation and that issues of enrollment will not be easily resolved, even with the creation of additional enrollment pathways.

"Despite having "universal coverage" for children in New York, families who have newly immigrated here will often not enroll their children onto public health insurance due to lack of trust in the system and fear for how obtaining public benefits can impact their immigration status. This lack of trust in immigrant communities needs to be overcome with careful design of our enrollment system, ensuring education for this population as a part of the process."

Lorraine Gonzalez, LCSW

To this end, a few participants suggested that community-based organizations and advocates be more involved in this aspect of the ACA.

"Community based organizations need to be involved to facilitate enrollment. They help to gain the trust of those in the community."

David Sandman, PhD

"They [at the state] need to make sure as many languages are offered as they can. Additionally, it will be important to include community outreach workers that have the same background as the people they are helping, providing eligible clients with places that are safe and comfortable to find what coverage options meet what they need."

M. Tracey Brooks, Esq.

A few other participants voiced concerns about the needs of special populations (e.g., homeless, runaway, foster care, LGBTQ youth). These youth are often hard to reach, difficult to engage, and are particularly vulnerable during transitional points.

"[New York] is moving to transition everyone in Medicaid to managed care, including those in the foster care system. The challenge is going to be how to handle the transition for this highly vulnerable population to make sure these kids get the care they need."

Kate Breslin, MPH, MCRP

VI. Special Issues for Adolescents and Young Adults

Participants were asked about the extent to which the needs of adolescents and young adults were being addressed in health care reform efforts at both the state and Federal level. All interviewees agreed that expanded health coverage under the ACA is beneficial for adolescents and young adults. As stated by one informant:

"With the ACA, almost everybody (with the big exception of undocumented persons) will have insurance, making it much easier to improve health care for the poor, teenagers, people without jobs, low income individuals, and those in the informal sector. It is hoped that it will also reduce the need for health centers or clinics to rely on grant funding or charity funding in order for their health center or clinic to work."

John Santelli, MD

However, the interviews revealed a number of special considerations for adolescents and young adults including: (1) the relationship between New York's "Age 29" law and expanded coverage for young adults up to age 26 under the ACA; (2) the challenge of maintaining confidentiality with Explanation of Benefits (EOBs) sent to policy holders as well as use of electronic health records (EHR); and (3) the ability of the Exchange to manage the influx of adolescents and young adults gaining coverage.

1. Comparison of New York's "Age 29" Law with the ACA's expansion to age 26

Prior to the ACA, New York initiated its own state-based effort to expand coverage for young adults under what is commonly referred to as the "Age 29" Law. Passed in 2009,⁴³ this legislation extended health insurance benefits to young adults living in New York who are under age 30, unmarried, and not eligible for employer-sponsored insurance or Medicare.⁴⁴ Under New York's "Age 29" law, eligible young adults aged 18-29 years can continue or obtain coverage through their parent's policy, which cannot be more than 100% of the individual premium rate,⁴⁵ though the employer is not required to pay any part of the premium.

As noted previously, expanding health coverage for young adults up to age 26 was one of the major thrusts within the ACA to address this large segment of the uninsured population. As a result, private health insurance companies are required to enable parents to obtain coverage for their dependents up to age 26 in the employer-sponsored and individual health insurance markets. The ACA provides benefits for young adults up to age 26 that are much better than those under New York's "Age 29" law. NY's law allows young adults to *purchase* group coverage through their parent's employer and allows young adults to take advantage of the group rate. However, New York's "Age 29" law does not require the parent's employer to make a contribution to the premium.⁴⁴ Thus this coverage can be quite expensive. In contrast, under the ACA young adults up to age 26 can be added to their parent's policy *as a dependent*. Thus, there could potentially be no additional out-of-pocket cost for the parent, or it is possible that the family's cost would be the difference between single and family coverage. A few respondents discussed how the ACA improves coverage for young adults up to age 26; however, there is still concern about adequate, affordable coverage for the young adult population.

"The policy for dependent young adults to age 26 [under ACA] is better than what we currently have in NY, which is more along the lines of COBRAⁱⁱⁱ."

David Sandman, PhD

"Expanded coverage to age 26 is better under ACA, but for those young adults who are lucky enough to have parents who have insurance and have the ability to afford it, those are the young adults who are going to fare better."

M. Tracey Brooks, Esq.

2. Challenge of maintaining confidentiality

Confidentiality is a basic tenet of adolescent health care services^{21,46}; however, there are several issues involved in ensuring that adolescents and young adults have access to confidential health services. First, there are minor consent laws for adolescents under the age of 18 that provide a legal basis for minors to give consent for their own health care and, in some situations, also provide a basis for confidentiality protections. While these minor consent laws and confidentiality protections vary from state to state, they usually begin at 12 years of age or older and cover a range of reproductive health, mental health, and substance use services.^{47,48} There are also protections about the sharing of personal health information under the Health Insurance Portability and

ⁱⁱⁱ Consolidated Omnibus Budget Reconciliation Act (COBRA) is federal law that extends your current group health insurance when you experience a qualifying event such as termination of employment or reduction of hours to part-time status.

Accountability Act (HIPAA) for minors, as well as for adults.^{49,50} With the expansion of health care coverage and health care reform efforts under the ACA, concerns are again raised about the need for adolescents and young adults to have adequate confidentiality protections and assurances to ensure their access to sensitive services.

There are a number of ways in which confidentiality could be breached, particularly in private health insurance plans.⁵¹⁻⁵³ First, Explanation of Benefits (EOBs) for services rendered can be inadvertently sent to the primary plan holder (e.g., a parent) and other disclosures that occur during the insurance claims process can potentially include confidential health information that can affect both minors and young adults. Second, there are concerns about the need for confidentiality protections for both adolescents and young adults with regard to the use of electronic health records (EHR). Third, if adequate protections are not in place, eligibility and enrollment can present potential additional risks, if it occurs at point of care when sensitive services are being accessed. Many participants in this study, especially among health advocates and health care providers, expressed concern that there was inadequate attention being paid to the importance of assuring confidentiality among both the adolescent and young adult population. They felt that this population was not getting enough attention because of the other “more pressing” policy decisions related to the need to create the necessary health system infrastructure within health care reform, as well as the considerable uncertainty regarding the implementation of the overarching health policy legislation at both Federal and state levels.

New York has made significant efforts to protect the confidentiality of adolescents and young adults. For instance, New York does not require health plans to send an EOB if the patient pays any required copayment at the time of service and the balance of the provider’s fee will be paid directly by the health plan.^{51,52} In addition, under New York’s current law, a minor who understands the risks and benefits of proposed and alternative treatments can consent to reproductive health care on their own including comprehensive family planning, abortion and pregnancy care; care for sexually transmitted infections; mental health services under many circumstances; certain alcohol and drug abuse services; and sexual assault treatment.⁵³ Health care providers can also treat minors in an emergency without parental consent.⁵³ In addition, health care or mental health professionals may not disclose confidential information about a patient without the permission of the person who consented to the health care (unless otherwise specified by law). New York’s Medicaid Family Planning Waiver (e.g., the Family Planning Benefit Program [FPBP]) enables teens to enroll based upon their own income level, rather than their parents’ income eligibility (all program clients are

eligible up to 200% of poverty) and give their own consent for services. FPBP, like other Medicaid coverage for sensitive service, does not send EOBs. The previously mentioned confidentiality provisions apply to all health plans including publicly-funded insurance programs (i.e., Medicaid and New York's Child Health Plus program). Most of the participants were well informed about New York's existing confidentiality provisions for minors.

"NY has a pretty comprehensive set of minor consent laws allowing minors to receive confidential services. The provisions allow youth to receive certain essential care without parental knowledge."

John Santelli, MD

"Public Health Law delineates the confidential services available to minors, and in New York minors are able to qualify for the Medicaid-based Family Planning Benefit Program under their own income."

M. Tracey Brooks, Esq.

"Teens older than 13 can access reproductive health care, without parental consent – not just Title X, but across the board."

Ellen Rautenberg, MHS

With the expansion of health insurance coverage resulting from the ACA significantly more young adults under age 26 will be covered under their parent's plan, which raised concerns about the risk of an EOB sent to the primary policy holder (typically the parent). In this event, confidentiality could be violated because someone else (i.e., parent) will know what services an adolescent or young adult has received because of the information provided in the EOB. It is possible that health care providers as well as newly insured adolescents and young adults may not be aware of this requirement and its potential repercussions on this age group. Most of the interviewees expressed a great deal of concern that the confidentiality of adolescents and even young adults is at risk, especially for those who will access health insurance through their parent's health plans. While laws currently provide some confidentiality protections for adolescents and young adults who seek health care services, these laws generally do not address the insurance claims process. Unless confidentiality can be assured in the enrollment process and in the EOBs for services rendered, then adolescents and young adults may not access care that is available to them under the ACA.

The majority of the respondents discussed the need to maintain adolescents' access to health care (including confidentiality protections), as well as to address the special

situation of young adults continuing to receive health care under their parent's health plans.

"EOBs are the insurance company's way of preventing fraud. This [requirement] forces disclosure for the service providers. Forcing an EOB on the policyholder, who may not be the same person who is seeking services, potentially violates patient confidentiality. This is a national issue. The American Congress of Obstetricians and Gynecologists, the Society for Adolescent Health and Medicine (SAHM), and the American Academy of Pediatrics (AAP) are aware of this issue and are working on a policy statement."

John Santelli, MD

"Once in the provider's office, there is often an awareness for the need for confidential care. The insurance infrastructure, however, is often misaligned with the New York State minor consent and confidentiality law. This is mainly manifested by the Explanation of Benefits (EOB) that gets sent home to the primary insurance member...When you add in the electronic health record challenges to the insurance issue of EOBs, there are likely going to be unintended confidentiality breaches."

Alice Berger RN, MPH

"It is great individuals are covered under their parent's insurance, but for those with private coverage, EOBs are still being sent home. In New York State, EOBs must be sent home by law in private plans."

Deborah Kaplan, PA, MPH

New York has some protections against confidentiality breaches associated with EOBs. For instance EOBs cannot be sent to a policy holder if payment for services have been received at the time service is rendered; and EOBs for sensitive services are only to be sent to the patient as specified by the patient). However, most states do not have clear statutory or regulatory directives regarding EOBs, denials, and acknowledgement of claims and/or payments of claims.^{51,52} Another challenge is that there may be a conflict between the provisions of state insurance laws governing communications that occur in the insurance claims process and state laws that provide confidentiality protections for health care information.⁵³ Thus, as emphasized by many of our interviewees, the challenges of protecting confidentiality of adolescents and young adults, especially for sensitive services, is still present even in the context of New York state with its long-established history of protecting young people's confidentiality.

The Health Information Technology for Economic and Clinical Health Act, or HITECH Act, establishes incentives for the adoption of electronic health records (EHRs).⁵⁴ While

this is not part of the ACA, three participants reported concerns about the Federal push towards implementing EHRs and the unintended consequences that they may have on limiting the ability to protect the confidentiality of health services for adolescents and young adults.

“Electronic health records generate information that may be shared by young people who assume that it is confidential, but parents will have access.”

Richard E. Kreipe, MD

“Electronic medical records make medical records more accessible, giving parents the full access to their child’s complete medical record...Parents may be looking at the current admission and may find notes from previous visits [such as] family planning, sexually transmitted infections, etc...”

John Santelli, MD

Adolescent health care providers and advocates have struggled with confidentiality issues over the past several decades. They discussed the need to maintain adolescents’ access to health care, including confidentiality protections, as well as address the special situation now that young adults can continue to receive care under their parent’s health plans. For many of the interviewees, the eligibility requirements (e.g., Social Security number) and use of EHRs heighten existing concerns about protecting confidentiality for adolescents and young adults.

“I am concerned [the Exchange] may not continue to protect the confidentiality of adolescents and minors for reproductive health care. There are already barriers and I hope [the Exchange] does not add new problems...We are never going to not need confidential services.”

Deborah Kaplan, PA, MPH

3. The ability of the Exchange to handle the influx of newly covered adolescents and young adults

Since the implementation of the ACA significantly more young adults nationally have gained access to health insurance through the provision that allows them to maintain coverage as part of their parent’s health insurance plan.⁵⁵ While all participants cited this as an extremely positive aspect of the ACA, five study participants discussed their concerns regarding the number of providers available to care for this population, as well as the need for extended visit time to provide comprehensive and confidential care to this influx of newly insured young adults.

“The plans are really the administrative shell. What it really gets down to is whether the network of providers... are ready for the influx.”

Alice Berger, RN, MPH

“I would rather see an influx in the number of patients I see every day rather than what is happening now; adolescents using the emergency room for care instead of getting primary care... There is a need for more providers.”

Elizabeth Alderman, MD

One participant mentioned the need to implement a medical home model for adolescents and young adults in order to provide them with essential comprehensive health care.

“The medical home could provide teens with access to a selection of providers who love working with teens, building a certain level of trust that is needed when working with teens [and] enabling them to provide more comprehensive care.”

Deborah Kaplan, PA, MPH

Overall, the interviews captured issues relating to the added pressures on health care access and quality under the ACA—especially for vulnerable populations—as well as strategies for alleviating some of these pressures. Specifically, participants noted that as more previously uninsured people enter the marketplace and Medicaid is expanded, there is a need to have streamlined enrollment systems that can accommodate the diverse needs of this “incoming” population, as well as accommodations for the fluctuations in patients’ eligibility for various systems of care that result from inevitable changes in family income, employment, and family composition.⁵⁶ In addition, there is pressure on the current capacity of providers to care for the expanded patient population, especially in traditionally underserved areas (e.g., rural and low-income). Some consider expanding the use of nonphysician providers (e.g., nurse practitioners and physician assistants) for comparatively healthy populations as a possible strategy for increasing the supply of primary care providers.⁵⁷

There is also growing interest in the use of health information technologies, such as the Internet and mobile devices, to improve access,⁵⁸ which may have a special appeal for adolescents and young adults.⁵⁹ However, there will also be a need for changes to models of health care training and health care delivery in order to harness new strategies aimed at increasing health care access, capacity, and quality. Approaches aimed at improving the access and coordination of care include the “patient-centered medical home,” in which a single provider coordinates care for individual patients. Accountable Care Organizations (ACOs) are likely to adopt some aspects of the medical

home model and will represent a larger proportion of health care delivery systems going forward as they are recommended as a model of care under the ACA.⁶⁰ How these models are implemented and evaluated over the next several years will be critical to understanding their impact on health care access, quality, and cost in general, with particular regards to adolescents and young adults.

VII. Closing Reflections

At the end of each interview, participants were asked to reflect on and discuss what they felt were the most successful aspects, as well as significant challenges, related to health care reform to date. Overwhelmingly, participants cited the expanded health insurance coverage for young adults up to age 26 and the prevention of excluding coverage for individuals with pre-existing health conditions (already in effect for children, and due to be implemented in 2014 for all age groups) as the most significant, immediate successes. Participants also hailed the requirement of health plans to cover recommended preventive services without cost sharing as particularly beneficial for children, adolescents, and young adults. In addition, the expansion of Medicaid in New York and the opportunity to improve the affordability of care were also cited as strengths of the ACA. However, despite these successes, a number of significant challenges remain. These include integrating state and Federal health policies, allowing adequate time to plan for successful implementation of all aspects of health care reform, acquiring sufficient financial resources, and building the necessary coordination with existing infrastructures.

Interviewees discussed the need to address a multiplicity of challenges regarding access to health care coverage and health plan enrollment, both currently and over time, as the ACA is fully implemented as intended. Such challenges include: (1) educating families and individuals about their eligibility and resources for health care; (2) streamlining the enrollment process and maintaining continuity of care despite fluctuations in income that result in eligibility changes; (3) assuring the confidentiality of sensitive services for adolescents and young adults; (4) the need to change the culture of care-seeking behavior among adolescents and young adults (e.g., accessing preventive health services rather than waiting until they have an identified health problem); (5) ensuring these populations fully understand the implications of catastrophic coverage; and (6) ongoing concerns about adequate reimbursement for providers. While the ACA makes it easier to provide services to adolescents and young adults through increased access to affordable health care coverage, Dr. Elizabeth Alderman noted, “there are issues about how the pediatrician or family medicine doctors are going to be compensated.” According to Tracey Brooks,

“appropriate levels of reimbursement for providers are necessary to provide adequate care.” However, reimbursement issues are not new or unique to the ACA, as Alice Berger commented, “reimbursement to adolescent health care providers has always been and will always be pivotal.”

There are a number of ongoing challenges related to the affordability of care, which include but are not limited to balancing clients’ needs for health care affordability with an adequate reimbursement rates for providers. Providers who care for adolescents and young adults need sufficient clinical time and reimbursement to conduct a thorough health history and offer the array of recommended clinical preventive services, as well as respond to the other clinical needs of their patients. Related to this issue, as well as the likely pent-up demand through the anticipated expansion of health care, is the need to increase the number of providers who are adequately trained to meet the needs of adolescents and young adults among many other populations in need.

VIII. Conclusion and Implications

The purpose of this case study was to capture a snapshot of health care reform efforts and their implications for adolescents and young adults in New York State. The interviews were conducted at a time of tremendous uncertainty related to the impending Supreme Court decision regarding the survival of ACA. A number of adolescent and young adult health experts and advocates noted concerns regarding several issues that will impact the overall intent of the ACA to expand coverage to young adults and low income populations. With New York’s exceptional history of successful health initiatives aimed at responding to the unique needs of adolescents and young adults, it is important to examine the context of its strategic planning efforts within the implementation of the Exchange and Medicaid expansions (among other key elements of the ACA). This is particularly significant now that the Supreme Court has largely upheld the constitutionality of key provisions of the ACA. There are several implications that cut across each of these topic areas that require strategic planning in order to adequately prepare for ACA requirements as well as implementation.

1. Implementation requirements

The first overarching issue concerns implementation requirements necessary to adequately meet the needs of adolescents and young adults. Efforts to reform health care involved examining the existing systems that serve adolescents and a careful consideration of how to truly coordinate new health care reform requirements that impact these systems without compromising access, quality, and affordability of health care services. The experts interviewed in this case study indicate that New York has a

number of existing confidentiality statutes, as well as outreach and enrollment systems, that have helped meet the unique health problems of adolescents and young adults in this state. New health reform requirements need to build on and coordinate with these systems to improve access to and the delivery of health care for these special populations. With multiple funding streams for health care subsidies and the diverse needs of patient populations, differing solutions have emerged at various levels of government-Federal, state, county, and city-often resulting in a patchwork of services and solutions. Integration and coordination at the local level is critical to the successful implementation of requirements for Federal and state reforms. This includes assuring potential links between public and private health care markets and expanding health care subsidies, thus, enabling many who have not previously been able to afford and access health insurance to obtain coverage and the health care they need to assure improved health outcomes and well-being.

Participants also stressed the need for coordination efforts to be proactive, so that they can comply with Federal reforms in ways that support previous state and local initiatives. Over time, the ACA would require that a number of the existing categorical health programs to be incorporated into a streamlined system of health care financing. Conceptually, this integration would reduce the current creative mosaic of fragmented sources of funding, services, and eligibility endemic in the current health care system. Recognizing that this is a complex process that will require a period of transition, many professionals and advocates representing diverse sectors will need to identify effective approaches for orchestrating such a complex web, while also assuring that the unique needs of the populations they represent will continue to be met in any new and emerging system of health care delivery and financing.

2. System preparedness and capacity

Over the past decade, there has been a technological revolution with a number of Federal and state initiatives to move towards developing and implementing information technology systems to improve the administration and efficiency of health care (e.g., electronic medical records and other health information systems). While information technology is one component of system preparedness, the capacity to serve special populations is another key issue. How the technology system is set up, managed, protected from security breaches, compliant with confidentiality protections and accessed in ways that are user-friendly to multiple stakeholders (e.g., individual consumers, providers, eligibility regulators, insurers) is complex and rapidly evolving.

Another example of the need to invest in system infrastructure and capacity is reflected in the priority articulated within the ACA towards preventive health care, including the delivery of preventive health services for adolescents and young adults. If such a vision is to be fully actualized, we will need to recognize that existing systems of care may not be adequately designed to conduct comprehensive health risk assessments and deliver the necessary preventive health services incorporated into the ACA framework. This broader delivery model will likely require greater amounts of time possibly from a broader array of professionals (e.g., counselors and educators) than the traditional 10-30 minute health visit. Adequate reimbursement for the delivery of such preventive services will need to be built into the system, including potential bundled payment reimbursement.

There are also capacity issues regarding the training of health care providers and the availability and distribution of sufficient numbers of trained health care providers who are prepared to meet the demands of this new growth in the insured population. A primary challenge will be the integration of nonphysician providers and health information technology into the care of adolescents and young adults, to deliver comprehensive behavioral, mental, reproductive, and physical health care services across different providers, settings, and health systems. At the same time, there is a need for systems of care to ensure that the confidentiality of sensitive health services can be maintained.

3. Financial support

The primary goals of health care reform efforts, including those within the ACA, are to address the rising health care costs and make health care more accessible and affordable. Under the ACA, the Federal Government will increase the number of persons eligible for Medicaid and subsidized private health insurance coverage. It will also create a more competitive and regulated health insurance marketplace. However, there is a great deal of uncertainty about whether or not Federal subsidies available through the Exchange will be sufficient to address the needs of low income individuals at different levels of “poverty” who will be eligible to receive financial support to offset the costs of health care insurance. While consumers will have different options for health plans and benefit packages, there will be associated costs and benefits to each of the options. For lower income populations and young adults, one of the biggest concerns is the potentially negative unintended consequence of youth selecting Catastrophic Care as an attractive option due to its lower premium cost, leaving these populations with only limited coverage of their necessary preventive and primary care health services.

4. Preparation for individual health care consumers

A great deal of consumer education will be required to prepare individuals, particularly young people, to understand various options, enrollment requirements, costs, subsidies, and exemptions. Individuals with less education, the economically disadvantaged, and immigrant populations will require special efforts. In addition, there needs to be a cultural shift, especially among young adults, to seek preventive health care services, as this population—even when insured—traditionally seeks care only for health problems rather than proactively seeking services for their health and well-being.³ To date, little is known about how young adults will evaluate available health care options and what impact those choices have on where they turn for health services—especially sensitive services where confidentiality can be assured. In addition, the availability of social media and the internet holds promise for educational and counseling opportunities, including health assessments that can occur in the privacy of someone’s home and before and following the visit. If such technology is harnessed, providers can better tailor their interactions with clients both during and after clinical visits. IT approaches, such as subsequent emails and text message reminders, may be especially useful in providing critical client reinforcements for instances such as assuring compliance with medication or changes in dietary practices.

5. The unique contribution of adolescent centered health systems

In sum, health care systems such as the MSAHC will likely continue to play a critical role in the provision of health services to adolescents and young adults. They will potentially serve more adolescents and young adults as coverage for these populations is expanded. The funding streams and associated eligibility requirements will be different than what currently exists and the impact of this is not clear; however, participants expressed concerns that even with ACA’s expansion of care, barriers to access will continue to need to be addressed. Maintaining confidentiality of adolescents and young adults is a significant challenge especially in the billing of insurance for services rendered. This could have a detrimental impact on the extent to which youth (even those with insurance) will access care. Under current conditions, many of the apparently eligible young people seen at MSAHC end up without an insurance product. Thus, issues of enrollment and access will not be easily resolved, even with the creation of additional enrollment pathways. However, health care delivery services who currently deliver care with a broad array of providers and funding streams (e.g., MSAHC, school-based clinics, and other community clinics) have the potential to help adolescents and especially young adults reconceptualize care with an emphasis on prevention. MSAHC’s mission to treat adolescents as educated consumers of care may

mean that they are well positioned to help youth navigate the enrollment system and the Health Benefit Exchanges. In addition, they may also be in a better position than other clinics to adjust to the changes in eligibility and funding streams. Yet, even with their “nimbleness,” there will still be a significant impact of this health care reform, if fully implemented. Building upon their past and current successes as a learning community devoted to the needs of young people, they—and other providers in New York State—will need to be poised to adapt to new requirements with pending policy decisions. They will need to continue to prioritize their efforts as systems of health care delivery and financing undergo major changes in the years to come.

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