

The Affordable Care Act and the I/DD Community

An Overview of the Law and Advocacy Priorities Going Forward

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Introduction

People with intellectual and developmental disabilities (I/DD) have long faced significant and persistent barriers in health care access and outcomes. The passage of the Patient Protection and Affordable Care Act of 2010 (Public Law 111-148) offers unique opportunities to improve the health care experiences of people with I/DD. The majority of public attention regarding the ACA has focused on the goal of universal coverage. Yet, for people with I/DD access to health insurance coverage has never been the primary challenge. This population has been primarily covered by public health insurance options, such as Medicaid and Medicare. Although most people with I/DD receive health insurance benefits, research has consistently demonstrated significant disparities in access to quality healthcare for members of the I/DD community. Thus, it is critically important for policymakers and advocates to recognize the ACA's substantial impact on healthcare for people with I/DD.

If the ACA is going to succeed in accomplishing its objectives, equal weight will need to be placed on successfully implementing its provisions relating to scope of benefits, access to providers, and meaningful long-term services and supports. This issue brief will analyze the implications of the ACA for people with I/DD, with particular emphasis on both the impact of ACA's implementation to date and systems change opportunities with respect to parts of the law scheduled to come into effect over the course of the next several years. We will outline the effects of ACA-mandated policy reforms to Medicaid, private insurance and other aspects of our nation's healthcare system.

Universal Coverage: Health Insurance Exchanges, Essential Health Benefits and State Medicaid Expansion

Starting in 2014, Exchanges, or marketplaces, in which individuals and small businesses can purchase health insurance, will be established at the state and national levels. At the same time as the exchanges become available, all Americans will be required to possess health insurance or face a financial penalty, unless they can demonstrate sufficient financial hardship preventing them from doing so. Subsidies for purchasing health

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The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities. www.autisticadvocacy.org

insurance will be offered to people who earn between 100% and 400% of the federal poverty level (as of 2013, the FPL stands at \$11,490 for a one-person household). The function of the ACA's exchange system will be to offer a marketplace where those seeking to purchase health insurance will have access to affordable options. The function of the exchanges is to purchase private health insurance – as a result, the ACA's provisions include significant reforms to private insurance markets, some of which are already in place.

Under the protections that are already in place as a result of ACA, health insurance companies are prohibited from:

- imposing lifetime limits on the dollar value spent on covering care and services;
- rescinding coverage except in cases of fraud;
- imposing annual limits on the dollar value of coverage below certain amounts (annual limits will be eliminated entirely as of 2014); and,
- denying coverage to children based on pre-existing conditions. Before the ACA, insurance companies often placed annual and lifetime spending caps on coverage, creating a significant financial barrier for individuals who require frequent or long term health services.

With the establishment of the ACA's exchange system, the private insurance reforms the ACA requires will come into full effect. Most notable among these is an end to pre-existing condition discrimination for people of all ages. Under the current private insurance model, insurers can (and do) charge a higher price for coverage to people with disabilities, chronic health conditions and other statuses that suggest a person is more likely to need healthcare services. With the establishment of the exchange system and the full scope of the ACA's private insurance reforms coming into effect, insurance companies will not be able to charge people with disabilities more on the basis of their disability or other health condition. Insurers will only be able to vary prices on the basis of age, tobacco use, family size and geography¹.

Plans wishing to be available for purchase on the exchange must meet certain requirements to be considered Qualified Health Plans (QHPs). By becoming a Qualified Health Plan, plans are eligible for inclusion in the exchange marketplace and its associated subsidies. The Affordable Care Act states that each plan must offer a minimum set of "essential health benefits" (EHB), which must include items and services within at least the following ten categories:

- ambulatory patient services;
- emergency services;
- hospitalization;
- maternity and newborn care;
- mental health and substance use disorder services, including behavioral health treatment;
- prescription drugs;
- rehabilitative and habilitative services and devices;
- laboratory services;
- preventive and wellness services and chronic disease management; and,
- pediatric services, including oral and vision care².

In February 2013, the US Department of Health and Human Services (HHS) finalized regulations defining the essential health benefits (EHB) package under the law. Rather

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than choose to set a single federal definition of essential health benefits, as many in the disability advocacy community preferred, HHS decided to define “essential health benefits” in relation to a state-selected benchmark plan³. States may pick from several options, including the largest small group private health insurance plan by enrollment within that state. All plans wishing to be considered Qualified Health Plans eligible for the exchange must have benefits that are substantially equal to the benefits offered in the state-selected benchmark plan. States may set criteria allowing plans to substitute within most of the 10 essential health benefits categories. However, the final plan must be actuarially equivalent to the benchmark plan and no substitution may occur within the prescription drug benefit⁴. In addition, states may prohibit benefit substitution altogether. In those states that allow it, insurance companies may not substitute benefits in a way defined as discriminatory by their state⁵. To help facilitate transparency and consumer choice, exchanges will sort plans by their actuarial values. Consumers will be able to review what “metal level” a plan has been sorted into in order to assess the relative generosity of available plans – a bronze plan will have an actuarial value of 60 percent, a silver plan an actuarial value of 70 percent, a gold plan an actuarial value of 80 percent and a platinum plan an actuarial value of 90 percent⁶.

Certain essential health benefit categories, such as habilitative services (services, like occupational therapy or speech pathology services, that are designed to help someone acquire new skills), are either absent or only minimally present within existing private insurance options. This presents a significant obstacle, as the essential health benefit package is defined in relation to a state-selected benchmark plan from available private insurance options. In other words, the minimum essential health benefits required of Qualified Health Plans on the exchange are set in relation to what is currently available in the private insurance market within that state. To address this, the Department of Health and Human Services (HHS) specifically clarified in their final regulation that states should have the flexibility to determine the services included within the habilitative services category⁷. In the event that a state does not determine habilitative service benefits, a health insurer must either “provide parity by covering habilitative services benefits that are similar in scope, amount and duration to benefits covered for rehabilitation services; or decide which habilitative services to cover and report on that coverage to HHS⁸.” The regulation explicitly clarifies that this is intended as a transitional policy, likely to be revisited and refined in the future. It also clarifies that HHS intends to carefully monitor habilitative services coverage across the private insurance market, with an eye towards making changes to this policy in the future.

The Affordable Care Act provides states with a number of key policy decisions to make before January 2014, when the law’s insurance reforms and the accompanying individual mandate to purchase health insurance will come into effect. States are encouraged to set up their own health insurance exchanges within broad parameters outlined by the law. States that choose not to set up their own exchange may partner with the federal government to establish a jointly run “partnership exchange”. In the event that they do not do so and have not set up their own exchange, their residents default into a federally run exchange system. As of May 2013, 17 states have elected to set up their own exchanges, 7 have decided to utilize partnership exchanges in conjunction with the federal government and 27 defaulted to the federal exchange.

A key component of the ACA’s purpose was to ensure universal health insurance coverage. As a result, individuals who earn below the federal poverty level who would

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not qualify for exchange subsidies were intended to be covered by an expansion of state Medicaid programs to include all adults under 133% of the federal poverty level. . . Before the Supreme Court's 2012 decision *National Federation of Independent Businesses vs. Sebelius*, the Medicaid expansion was a mandatory component of the ACA set to take effect in 2014. However, the Court ruled that the federal government lacked the ability to penalize states who failed to expand Medicaid, resulting in the expansion shifting to an option. Due to conflicts within states and ongoing negotiations with the federal government on potential areas of flexibility for implementing the Medicaid expansion, it is still unclear which states will participate. However, as of May 2013, the Kaiser Family Foundation reported that 29 states have opted to expand Medicaid, 20 states have indicated that they will not do so and 2 are still weighing their options⁹.

The Medicaid expansion is likely to have a particular impact on people with intellectual or developmental disabilities who do not qualify for Supplemental Security Income (and, as a result, Medicaid) either due to not meeting functional impairment criteria or earning too much money, but who nonetheless struggle to access the private health insurance market. This population is likely to include the many adults on the autism spectrum who do not meet functional impairment requirements for SSI and/or Medicaid waiver services. It should be noted that even in those states that do participate, states are not required to offer childless adults complete Medicaid benefits. Instead, states must offer limited benchmark plans that include a selection of benefits similar to what is offered by private insurance in that state. These benchmark packages include inpatient and outpatient hospital services, x-ray and lab services, physician services, mental health services, well-child care, and prescription drugs.

Key Advocacy Priorities

- At the federal level, disability advocates must work to pressure to adequately monitor state approval processes to determine which insurers will be considered Qualified Health Plans placing particular emphasis on the availability of “habilitative services” to Qualified Health Plan beneficiaries.
- HHS should work quickly to move beyond its current transitional policy on habilitative services and establish a strong federal standard for inclusion of habilitative services within the Essential Health Benefits Qualified Health Plans are required to offer to beneficiaries.
- In states establishing exchanges on their own or in collaboration with the federal government, state disability advocates should work together with state policymakers to craft exchange designs and Qualified Health Plan standards that meet the needs of people with intellectual and developmental disabilities. These exchange designs should place particular emphasis on the definition of Essential Health Benefits and the availability of adequate provider networks.
- Advocates should work to urge their state to either prohibit benefit substitution within EHB categories or to ensure their states carefully monitor the practice to avoid discrimination against benefits needed by people with I/DD.
- State level disability advocates should partner with their state's hospitals, health care providers and low-income advocacy community to urge their state to participate in the Medicaid expansion offered by the ACA.

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Medicaid Premium Assistance and the ACA's Exchanges

HHS has issued guidance on a variety of options available to states for the use of premium assistance —the use of public dollars to purchase private health insurance—to shift Medicaid eligible populations into the exchange system. Some states have communicated an interest in utilizing Section 1115 of the Social Security Act* for the purposes of experimenting with premium assistance programs to allow Medicaid and Children's Health Insurance Program (CHIP) beneficiaries to purchase Qualified Health Plan coverage on the exchanges established by the ACA.

Although the law gives the HHS Secretary broad discretion to authorize such demonstrations, in March 2013 HHS announced that it would only consider Section 1115 waivers for premium assistance that were limited to adults newly eligible for Medicaid as a result of the ACA's Medicaid expansion. Furthermore, people with disabilities and a number of other beneficiary populations already eligible for Medicaid were specifically prohibited from inclusion in premium assistance demonstrations authorized by Section 1115 waivers.† Despite this, existing state plan options offer other opportunities for people with disabilities – including people with intellectual and developmental disabilities (I/DD) – to access Qualified Health Plans on the ACA's exchanges. Under state plan options, states do not need to request waiver authority from HHS and can more easily amend their Medicaid state plan to set up or alter a premium assistance to meet the needs of people with disabilities seeking to access QHP coverage through the exchanges. Although a variety of state plan options exist that allow for premium assistance, the authors of this brief have identified two options of particular relevance to people with I/DD: Section 1906 and Section 1905(a). Both of these are existing state plan options that states can utilize to take Medicaid or CHIP funds and purchase private health insurance for beneficiaries.

Section 1906 relates primarily to the use of Medicaid funds to pay premiums on eligible Employer Sponsored Insurance (ESI) plans. Enrollment can be voluntary or mandatory. To make use of this option, states must demonstrate that it is cost-effective as compared to the cost of coverage under the Medicaid state plan or Medicaid waiver. States must provide wrap-around coverage (additional coverage that provides for what Medicaid would offer that private insurance does not) supplementing private insurance to ensure that beneficiaries have access to the same scope of benefits and protections against excess cost-sharing as are available under the Medicaid state plan or applicable waiver¹¹. Section 1905(a) allows for states to use Medicaid funds to purchase private health insurance on the individual market. Enrollment is voluntary and subject to the same cost-effectiveness, cost-sharing and benefit protections applicable to Section 1906¹².

Medicaid premium assistance could present substantial benefits to people with I/DD. The issues of provider adequacy for Medicaid beneficiaries are well documented. By accessing the private insurance market, Medicaid beneficiaries might have access to

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* Historically, innovative program models have often been implemented utilizing the broad statutory authority under Section 1115 of the Social Security Act, allowing the Secretary of Health and Human Services to grant waivers to provisions of existing Medicaid law for the purposes of demonstrations projects that the Secretary determines promote the objectives of the Medicaid program.

† In justification of this prohibition, HHS made note of the broader benefits available to populations already eligible for Medicaid and stated that "Marketplace plans were not designed to offer broader benefits and could experience unexpected adverse selection due to enrollment of groups [currently enrolled in Medicaid]."

a much broader choice of clinicians and other providers than are currently available under traditional Medicaid. Additionally, since the insurance will still be purchased within the context of the Medicaid program, cost-sharing and wrap-around coverage will apply. This will ensure a scope of benefits and cost-sharing arrangements comparable to that provided for under traditional Medicaid.

The 1905(a) option may be particularly well suited for use by people with disabilities. Although HHS has issued regulatory guidance that would seem to enable greater use of 1905(a) in conjunction with the exchanges established by ACA, trends in private insurance markets seem to operate against the likelihood of widespread expansion of premium assistance to the non-disabled adult population. This is largely due to two challenges in meeting cost-effectiveness requirements of premium assistance state plan options.

First, Qualified Health Plans on the exchanges are anticipated to be much more expensive than the cost of Medicaid for the average beneficiary. It is possible that this obstacle can be overcome for specific high-cost Medicaid populations that have higher average expenditures per beneficiary, such as pregnant women or people with disabilities eligible for Medicaid through Supplemental Security Income or the Medicaid Buy-In. It will prove more challenging to show cost-effectiveness for the relatively low-cost population of non-disabled healthy adults.

Second, Employer Sponsored Insurance (ESI) is increasingly incompatible with the requirements of the Section 1906 premium assistance program. The number of low-wage employees with Employer Sponsored Insurance available has been in decline. This reduces the population of individuals simultaneously eligible for Employer Sponsored Insurance and Medicaid or CHIP coverage. Furthermore, under Section 1906, employers must contribute at least 40% towards the cost of the insurance premium, and states must pay all cost-sharing requirements in excess of those required by Medicaid or CHIP. Given the declining generosity of Employer Sponsored Insurance plans, the cost-effectiveness requirement in Section 1906 will be increasingly difficult for the average beneficiary to meet.

Beneficiaries who have significantly higher than average Medicaid costs are more likely to meet cost-effectiveness requirements. This will enable them to make use of these state plan options. Due to the ACA's ban on Qualified Health Plans charging higher premiums on the basis of health or disability status, it may prove cost-effective for states to shift high-cost beneficiaries into the exchange system and provide wrap-around coverage.

Key Advocacy Priorities

- HHS should issue additional guidance to states looking to make greater use of either the Section 1905(a) or the Section 1906 state plan options to enable Medicaid and CHIP beneficiaries to access Qualified Health Plan coverage from the newly established exchanges. Specific information should be provided on assessing cost-effectiveness requirements for particular high-cost populations.
- At the state level, advocates should work with their State Medicaid agency to facilitate shifting people with I/DD into the exchange system through the use of 1905(a) state plan option while utilizing Medicaid for wrap-around coverage and to cover the cost-sharing expenses of private insurance.

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What Impact Would Accessing the Exchanges Have on People with I/DD?

Provider Adequacy

Americans with intellectual and developmental disabilities typically have access to a broad scope of benefits through the Medicaid program. However, their access to and choice of providers are worse than what is available to people with private insurance¹³. This is due to the lower reimbursement rates Medicaid pays physicians as compared to both Medicare and private insurance. The Affordable Care Act includes several provisions that relate to the issue of provider adequacy.

First, with respect to the Medicaid system, the ACA provides for a temporary increase in Medicaid reimbursement rates for evaluation and management and vaccine administration services. This adjusts rates up to the more generous Medicare standards with the goal of attracting more participation of primary care physicians to the Medicaid program.¹⁴ Medicaid reimbursement rates vary from state to state, but on average, this would amount to a 73% increase in primary care physician compensation from Medicaid and an additional \$11.4 billion in investment in Medicaid primary care^{15, 16}. Unfortunately, administrative issues between the state and federal government have delayed the implementation of the rate increase, and the ACA only authorized the rate increase for a two-year period in 2013 and 2014. To facilitate greater provider access for Medicaid beneficiaries, Congress should act to make the Medicaid rate increase for primary care physicians permanent.

In addition to Medicaid reimbursement rates, the Affordable Care Act also includes provider adequacy implications for private insurance as well. As outlined earlier in this brief, the Medicaid premium assistance options available to states would allow for greater provider access for states and individuals who make use of them to access the private insurance market. Although private insurance generally possesses better provider access due to higher reimbursement rates as compared to Medicaid, the ACA also includes specific provider adequacy requirements for insurers wishing to be deemed Qualified Health Plans within the exchange.

To facilitate transparency during the plan selection process, Qualified Health Plans on the exchange will be required to make available a provider directory online and in hard copy to enrollees upon request. This provider directory would include information about which providers are not currently accepting new patients.¹⁷ Additionally, Qualified Health Plans must maintain “a network that is sufficient in number and types of providers, including providers that specialize in mental health and substance abuse services, to assure that all services will be accessible without unreasonable delay” and include “essential community providers¹⁸.”

To assess compliance with these provisions, the Center for Medicare and Medicaid Services will be engaging in a variety of oversight mechanisms. CMS will defer to state review processes where the state’s assessment process is deemed sufficient, and its network adequacy standards are considered consistent with or greater than those required by the ACA. In states without sufficient review processes, CMS will either utilize accreditation standards from an HHS-recognized accrediting entity in the commercial or Medicaid insurance markets or, for unaccredited insurers, require them to

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submit a network access plan to CMS demonstrating the insurer has standards and procedures in place to maintain an adequate provider network, consistent with the ACA's requirements¹⁹.

Advocates from the I/DD community should carefully scrutinize the issue of provider adequacy within the Qualified Health Plans on the exchange open to residents of their state. Unfortunately, many of the factors that will drive network adequacy assessments in the initial years of the ACA's exchanges relate to the inclusion of Essential Community Providers. Essential Community Providers are defined in statute as "providers that serve predominantly low-income, medically underserved individuals²⁰." Due to the lack of inclusion of people with I/DD within the federal definition of "medically underserved", the I/DD community may face significant difficulties making use of the ACA's network adequacy requirements to ensure that Qualified Health Plans contract with providers who are competent to serve the I/DD community. The Center for Medicare and Medicaid Services has indicated its intent to monitor network adequacy through complaint tracking and data collection from Qualified Health Plans over the course of ACA implementation²¹. To ensure that our community concerns are addressed, the I/DD community must plan to carefully document network adequacy issues impacting providers serving people with I/DD and provide this information to the Center for Medicare and Medicaid Services and its Regional Offices.

Systems of Care

Connected to the issue of provider access and choice is the need for health care infrastructure that is willing and capable of serving all adults with intellectual and developmental disabilities, including those with complex medical and behavioral needs. Although access to exchange coverage has the potential to benefit people with I/DD through increasing provider access and choice, concerns have been raised that by splitting people with I/DD into multiple insurance risk pools, less incentive will exist to finance necessary health care infrastructure to serve those with the most complex needs.

For example, a state Medicaid program may have an incentive to finance the development of a regional center on primary and specialty care needs of adults with intellectual disabilities to support the significant number of adults with intellectual disabilities enrolled in Medicaid. However, should the state's population of people with intellectual disabilities be spread out over multiple private insurance plans, it is unlikely that any individual insurer will make sizeable upfront infrastructure investments for a population that makes up only a tiny minority of their enrolled beneficiaries. For health care infrastructure that requires initial or ongoing investment beyond typical reimbursement rates, this may present a challenge.

To respond to this concern, state policymakers must look to the interaction of state Medicaid systems and the private insurance market. As outlined earlier, Medicaid will remain a major financing mechanism for health care and long term services and supports for people with disabilities even after full implementation of the ACA. States must utilize their Medicaid programs to finance key investments in needed infrastructure for supporting the health care needs of people with I/DD. By utilizing Medicaid dollars to build a system which can also interface with private insurance through a more typical provider-insurer relationship, people with I/DD will be able to benefit more fully from access to private insurance markets.

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Employment

Work is a key aspect of quality of life for both people with and without disabilities. For people with intellectual and developmental disabilities, health care and employment outcomes have a significant inter-relationship. The relationship between access to health care and employment for people with disabilities is well documented²². Additionally, individuals with I/DD also experience improved health outcomes when being served in integrated employment contexts as compared to day habilitation.

The opening of the individual health insurance market to people with disabilities may have a real impact on employment outcomes for people with I/DD. For individuals with I/DD that do not require long term services and supports, and have acute care needs that can be met by the Qualified Health Plans offered by the exchange, access to the exchange system and the availability of premium assistance up to 400% of the federal poverty level may significantly reduce existing work disincentives. Given that many recipients of SSI and SSDI are reluctant to enter the workforce for fear of losing access to public health insurance, the availability of an affordable private insurance alternative offers significant opportunities for enhanced workforce participation.

However, for those individuals with I/DD who require long term services and supports (such as those receiving Home and Community Based Services under a 1915(c) waiver or other Medicaid HCBS benefit) or who have acute care needs that go beyond the Essential Health Benefits required by their state exchange system, private insurance availability will not eliminate the need for the use of Medicaid for these beneficiaries. Although these populations may still wish to access Qualified Health Plan coverage, it will be necessary for them to do so within a context that allows continued access to Medicaid benefits. Several work incentive programs exist to allow working adults with disabilities to access Medicaid despite exceeding the income and work requirements of the Supplemental Security Income (SSI) program. The two most relevant such programs are 1619b and State Medicaid Buy-In programs.

Under 1619b, SSI recipients are able to maintain eligibility for Medicaid after they are no longer eligible for cash payments due to income from work. Beneficiaries utilizing 1619b are able to maintain their Medicaid coverage so long as their income does not exceed a threshold level specific to their state. This threshold level is based on the average Medicaid expenditure for the state a beneficiary lives in and the amount of earnings that would end SSI cash payments for that state²³. Section 1619 of the Social Security Act was initially created as a three-year demonstration project in 1980 by the Social Security Disability Amendments Act of 1980 (Public Law 96-265). The demonstration was extended and then finally made permanent in 1987 by the Employment Opportunities for Disabled Americans Act (Public Law 99-643)²⁴.

Under the Medicaid Buy-In Program, authorized by the Balanced Budget Act of 1997 and the Ticket to Work and Work Incentives Improvement Act of 1999²⁵, states set terms under which working people with disabilities may “buy-in” to Medicaid despite not meeting the income and work tests for eligibility for SSI. States have substantial flexibility to customize the income and resource limits of their Buy-In programs. Studies show that Medicaid Buy-In participation is effective at raising the earnings of a substantial amount of workers with disabilities who enroll in it²⁶. As of December 2008, 42 states were operating Medicaid Buy-In programs with a total nationwide enrollment in excess of 90,000²⁷.

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People with intellectual disabilities are more likely than other SSI beneficiaries to be working. However, of the SSI beneficiaries who do work, people with intellectual disabilities are less likely to participate in the Social Security Administration's work incentive programs, such as 1619(b). While only 4.6% of SSI recipients with all other disabilities work, 12.8% of SSI recipients with intellectual disabilities do so as of 2011²⁸. For individuals who fall into other developmental disability categories tracked by the Social Security Administration, the rates of employment were even higher – 18.3% of Autistic adults receiving SSI beneficiaries participated in the workforce as did 17.5% of beneficiaries with congenital anomalies. The existence of publicly funded employment services available through the Medicaid program, such as supported employment, likely play a role in explaining the higher rates of workforce participation among SSI beneficiaries with I/DD. This reinforces the importance of the Medicaid program for facilitating employment outcomes for people with I/DD.

However, though 25.1% of working SSI recipients with all other disabilities participated in 1619(b), only 15.4% of working SSI recipients with intellectual disabilities did so²⁹. As other research has shown that people with intellectual disabilities tend to have lower earnings and work fewer hours than other groups of people with disabilities, reduced risk of exceeding income restrictions for the SSI program likely explains the reduced participation in work incentive programs. Yet, anecdotal evidence suggests that earnings for adults with I/DD are held down in part because of fears of loss of benefits combined with the existence of low-wage employment settings, such as sheltered workshops, to which people with I/DD are disproportionately tracked into³⁰. Although this is unlikely to fully explain the difference between earnings of adults with I/DD and that of other people with disabilities, ignorance of work incentive programs may explain part of this disparity. Additionally, people with I/DD and their families have greater reasons to fear loss of Medicaid benefits than some other groups of people with disabilities, due to the central role that Medicaid-financed long term services and supports play in the lives of people with I/DD.

To ensure that individuals requiring long term services and supports are able to take advantage of the employment benefits associated with the opening of the private insurance market to people with disabilities, exchange design will need to include mechanisms to easily allow people with disabilities to enroll in work incentive programs, like 1619b and the Medicaid Buy-In, that will allow them to maintain Medicaid eligibility after they enter the workforce. Optimally, people with disabilities should have the opportunity to incorporate 1619b or Medicaid buy-in participation into their purchasing experience on the exchange system.

Key Takeaways

- Congress should act to make permanent the ACA's temporary increase in Medicaid primary care reimbursement rates.
- State Medicaid agencies should work to invest in health care infrastructure for people with intellectual and developmental disabilities that can be utilized by both the Medicaid and private insurance systems.
- The I/DD community should carefully monitor and document network adequacy issues with Qualified Health Plans within the exchange system. They should also work with CMS and its Regional Offices to enforce ACA's network adequacy requirements.

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- States establishing exchange systems should incorporate enrollment in state Medicaid Buy-In programs within the same online interface utilized by the exchange.
- HHS should promulgate technical assistance to states reinforcing the rights and enrollment mechanisms for beneficiaries seeking to access subsidies and Qualified Health Plan coverage through the exchange while at the same time enrolled in or planning to enroll in their state Medicaid Buy-In program.

Long Term Services and Supports Provisions of the Affordable Care Act

In addition to the exchange system and changes to the nation's acute care infrastructure, the Affordable Care Act created a variety of new state options with respect to the provision of Medicaid-financed long term services and supports (LTSS). Over the course of the last several decades, states have been working to shift their Medicaid LTSS infrastructure from a model in which people with disabilities and older adults received support only in institutional contexts to one in which services were delivered in community-based settings. Since the Supreme Court's 1999 *Olmstead v. L.C.* decision, in which the Court ruled that the Americans with Disabilities Act's integration mandate requires states to offer services in the community, this process has accelerated and been the source of substantial federal encouragement. The Affordable Care Act offers states a variety of new mechanisms to accelerate their shift from institutional to community-based LTSS.

Community First Choice State Option

The Community First Choice state option was created by the Affordable Care Act as section 1915(k) of the Social Security Act. The Community First Choice state option offers financial incentives to states that adopt it for the purpose of providing home and community-based services attendant care through the Medicaid program. States that opt-in receive a 6% increase in federal matching payments for costs associated with the program, specifically the provision of attendant care. The state is required to provide funding for assistance with activities of daily living and health-related tasks, back-up systems to ensure continuity of services and support, and training on hiring and dismissing personal care attendants. States are permitted to fund transition costs or any additional provisions in a person's individual care plan designed to increase independence.

In exchange for the 6% enhanced match, states must meet certain obligations with respect to the attendant care services provided under the state option. The Community First Choice state option prohibits caps on enrollment or waiting lists for attendant care services financed under the option. As a result, the Community First Choice can assist advocates working to expand services to eliminate state waiting lists. It can also assist advocates working to maintain existing services, with new federal funds allowing for the maintenance of existing services in the face of declining state budgets. Many of the states which have taken up the CFC, or plan to do so in the future, already possess a robust Medicaid personal care state plan option which also provides for an uncapped attendant care benefit. By taking up the CFC, states can "re-finance" existing services with the 6% enhanced match, making it easier to fight back to prevent or mitigate service cuts. California was the first state to have its application to take up the CFC state plan option approved by the Center for Medicare and Medicaid Services

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(CMS). Among the other states which have applied or are currently considering applying for the CFC are Arizona, Colorado, Louisiana, New York, Maryland, Minnesota and Montana³¹.

For the I/DD community, particular emphasis should be placed on the CFC's requirement that states not discriminate between populations of people with disabilities. Although attendant care benefits are frequently presented as relevant primarily for individuals with physical disabilities and the elderly, they represent a potential financing source for developmental disability services as well. State level advocates must work to encourage taking up the CFC state plan option within their state. They must also urge their state to include people with I/DD and their family members in Development and Implementation Councils that states are required to create to advise and oversee implementation of the CFC state option. I/DD advocates must consider how CFC-financed services will interact with existing Medicaid 1915(c) waiver services, the awareness of case managers, self-advocates and family members of CFC-financed services as an option for people with I/DD and the ability of people with I/DD currently on waiting lists to access CFC-financed services without negatively impacting their ability to seek access to the more comprehensive services available under the 1915(c) waiver.

The I/DD community should support full implementation of the Medicaid Community First Choice (CFC) state option as a comprehensive benefit which can meet the needs of people who would otherwise be eligible for the comprehensive, 24-hour, facility services of an ICF/ID (intermediate care facility for people with intellectual and/or developmental disabilities) or nursing home. CFC is designed to require the state to provide a comprehensive enough benefit to ensure that the individual can successfully live in the community while being flexible enough to meet the needs of each individual.

There are numerous important elements of the CFC provisions, some of which are discussed below. However, one overriding provision worth noting for service eligibility purposes, which appears toward the end of the CFC statutory language, is the following:

“(3) State requirements.—In order for a State plan amendment to be approved under this subsection, the State shall—

....

(B) provide consumer controlled home and community-based attendant services and supports to individuals on a statewide basis, in a manner that provides such services and supports in the most integrated setting appropriate to the individual's needs, and without regard to the individual's age, type or nature of disability, severity of disability, or the form of home and community-based attendant services and supports that the individual requires in order to lead an independent life;”

Essentially, the state must provide consumer controlled home and community-based attendant services and supports to individuals on a statewide basis in the most integrated setting appropriate for the individual, without regard to the individual's age, type or nature of disability, severity of disability, or the form of home and community-based attendant services and supports that the individual requires in order to lead an independent life. This is an important element of CFC and should be a guiding principle for advocacy efforts, bolstered by the other statutory elements of the program.

State level advocates must work to both encourage the CFC state plan option within their state and also urge their state to include people with I/DD and their family members in Development and Implementation Councils...

Regarding the details of services available, the CFC benefit requires the state to make available home and community-based attendant services and supports to eligible individuals, as needed, to assist in accomplishing activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing. Services must be provided under a person-centered plan of services and supports, based on an assessment of functional need, and provided in community settings (not facility-based settings).

- Attendant services and supports are not limited to “personal care services” as the name might imply in everyday use. The key terms above are defined as:
- Activities of daily living.—The term “activities of daily living” includes tasks such as eating, toileting, grooming, dressing, bathing, and transferring.
- Health-related tasks.—The term “health-related tasks” means specific tasks related to the needs of an individual, which can be delegated or assigned by licensed health-care professionals under State law to be performed by an attendant.

Instrumental activities of daily living.—The term “instrumental activities of daily living” includes (but is not limited to) meal planning and preparation, managing finances, shopping for food, clothing, and other essential items, performing essential household chores, communicating by phone or other media, and traveling around and participating in the community.

The statute further defines services in this way:

“(B) Included services and supports.—In addition to assistance in accomplishing activities of daily living, instrumental activities of daily living, and health related tasks, the home and community-based attendant services and supports made available include—

- (i) the acquisition, maintenance, and enhancement of skills necessary for the individual to accomplish activities of daily living, instrumental activities of daily living, and health related tasks;
- (ii) back-up systems or mechanisms (such as the use of beepers or other electronic devices) to ensure continuity of services and supports; and
- (iii) voluntary training on how to select, manage, and dismiss attendants.”

This language makes it clear that the services and supports can be used to assist people with I/DD to learn/acquire and maintain new skills. The I/DD community also believes that these definitions are broad enough to provide support to individuals in whatever circumstances they need in their daily lives to assist them to become more independent, including supporting the individual while at work. The following exclusions in (ii) were included in the statutory language to prevent “double dipping” with the funds from education and vocational rehabilitation programs. However, like similar language already in the law regarding the Home and Community-Based waiver, this language should not interfere with services where the individual is not actually receiving those same services from the educational or vocational rehabilitation system.

“(C) Excluded services and supports.—Subject to subparagraph (D), the home and community-based attendant services and supports made available do not include—

MFP [Money Follows the Person] already has a proven track record for people with I/DD and will continue to be a valuable tool for institutional closure and census reduction efforts.

...

(ii) special education and related services provided under the Individuals with Disabilities Education Act and vocational rehabilitation services provided under the Rehabilitation Act of 1973;”

....

Balancing Incentives Payment Program

The Balancing Incentives Payment Program is a temporary program designed to incentivize states to shift their Medicaid LTSS budgets away from institutional-based services and towards home and community based services. The program allocates a maximum of \$3 billion to be spent between October 1, 2011 and September 30, 2015. States eligible to participate in the Balancing Incentive Program are those with less than 50% of their Medicaid LTSS budget in non-institutional settings in Fiscal Year 2009. Those states with 25-50% of their Medicaid LTSS budget in non-institutionally based LTSS can receive a 2% enhanced match for such services if they commit to reach a total of not less than 50% of total LTSS expenditures in non-institutional settings by September 30th, 2015. Those states with less than 25% of their Medicaid LTSS budget in non-institutionally based LTSS can receive a 5% enhanced match for such services if they commit to reach a total of not less than 25% of total LTSS expenditures in non-institutional settings by September 30th, 2015.

Participation in the Balancing Incentives Payment Program requires states to implement certain structural changes to their Medicaid LTSS systems. These changes include a single entry point system (or “no wrong door”) for all LTSS applications, referrals, and functional and financial eligibility assessments; independent case management for individual service plans and continuous monitoring of service provision; and implementation of a core standardized assessment instrument to determine eligibility and appropriate services. The enhanced match can only be utilized for new or expanded home and community-based services and may not restrict LTSS eligibility further than those standards in place as of December 31st, 2010. To date, the following states have had applications for Balancing Incentives Payment Program participation approved: New Hampshire, Maryland, Iowa, Mississippi, Missouri, Georgia, Texas, Indiana, Connecticut, Arkansas, New York, New Jersey and Louisiana³².

The Balancing Incentives Payment Program (BIP) establishes specific targets for Medicaid HCBS expenditures and incentives to meet those targets for states with less than half of their Medicaid LTSS budget in community-based settings. Because eligible states must increase overall HCBS spending by a significant proportion, this program has the potential to drastically improve access to HCBS funding for many people with I/DD. BIP funding could be utilized to incentivize states to reduce or eliminate waiting lists for I/DD services. Additionally, BIP’s required program reforms could assist advocates urging states to adopt modernization of their state’s I/DD service-provision system. However, advocates must remain vigilant that crucial program features of state I/DD infrastructure are not eliminated when BIP participation requires states to consolidate assessment or eligibility determination tools. For example, the BIP’s requirement of a core standardized assessment instrument to determine service eligibility must not be allowed to result in an assessment tool that fails to take into account the ways in which the needs of adults with developmental disabilities differ from those of older adults.

The Balancing Incentives Payment Program is a temporary program designed to incentivize states to shift their Medicaid LTSS budgets away from institutional-based services and towards home and community based services.

Re-authorization of Money Follows the Person

The Money Follows the Person program was originally created as a demonstration project within the Deficit Reduction Act of 2005. Developed to help assist states in implementing their obligations under the Supreme Court's *Olmstead v. L.C.* decision, MFP provides funding to assist Medicaid-eligible individuals in transitioning from receiving services in institutional settings to community based support instead. For the first 12 months after a person with a disability or older adult leaves an institutional setting, the federal government will pay 100% of the costs of their services in the community. Almost 20,000 transitions from institutional settings occurred through the MFP program between spring 2008 and December 2011³³. According to the 2011 Annual Evaluation Report for the MFP program, approximately 97% of MFP participants with intellectual disabilities who move out of an institution remain in the community³⁴. The ACA re-authorized MFP until September 30, 2016, and changed the eligibility requirements to allow individuals who have resided in an institution for three months, rather than the original six, to receive funding from the program. The ACA also appropriated an additional \$2.25 billion for MFP. MFP already has a proven track record for people with I/DD and will continue to be a valuable tool for institutional closure and census reduction efforts.

Key Takeaways

- State level advocates should work to encourage their State Medicaid agencies to take up new state plan options established by the ACA to expand Home and Community Based Services.
- As states begin implementing the Community First Choice State Option, the I/DD community should be vigilant to ensure that implementation proceeds in an inclusive fashion and that people with I/DD are able to access the benefits of the new benefit.

Conclusion

The Affordable Care Act is the most significant change to our nation's health insurance system since the creation of the Medicare and Medicaid programs. As the ACA comes into full implementation in 2014, the disability community will have access to meaningful opportunities to enhance access to and the quality of health care service provision. To accomplish this, advocates, policymakers and researchers must collaborate to monitor implementation, identify barriers to the fulfillment of key policy objectives and structure necessary program changes. While the ACA sets up a distinct healthcare infrastructure through the establishment of the exchange marketplaces, close coordination with Medicaid and full use of the ACA's new and renewed Medicaid state options should remain a vital priority. The Affordable Care Act's impact on the I/DD community has already been significant. Through advocacy and collaboration between policymakers and I/DD community stakeholders, the positive impacts of the ACA can be strengthened and expanded in the years to come.

As states begin implementing the Community First Choice State Option, the I/DD community should be vigilant to ensure that implementation proceeds in an inclusive fashion and that people with I/DD are able to access the new benefit.

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