Disability Snapshot: ACA, Medicaid and Unintended Consequences for People with Disabilities

The implementation of the Affordable Care Act (ACA) has brought new opportunities for people to obtain affordable health insurance coverage beyond employer-sponsored insurance, either through Medicaid (in the 28 states that have expanded income eligibility) or a private insurance plan (offered through the new health insurance marketplace).

This snapshot is focused on challenges faced by people with disabilities who are eligible for health care coverage through Medicaid, but may experience painful gaps in coverage due to transition issues stemming from current state eligibility and application processes. Particularly vulnerable to these gaps are people with disabilities who need long-term care services, those in states that have different provider networks for their Medicaid categories, and youth transitioning to the adult system.

Overview

The Affordable Care Act offers some powerful opportunities for states and individuals to reduce the number of uninsured through new paths to coverage and insurance regulations that improve insurance products for people. The ACA also provides small businesses new opportunities to support their employees through more affordable coverage. Health & Disability Advocates (HDA), along with other advocates and policymakers, has supported these important changes and promoted both the passage and implementation of this law. However, one key concern we articulated early on was the need to establish processes to ensure that people with disabilities did not end up in the wrong eligibility "bucket" due to the infrastructure changes to Medicaid, including different coverage for the new ACA Adult Medicaid group.

Medicaid packages for people with blindness and disability, or "AABD" or "SSI Related" Medicaid, offer comprehensive coverage, including long-term care supports and services. (Eligibility for Medicaid Buy-In, spend down and other waiver options can also offer eligibility for long-term care services.) Long-term care services and supports, such as personal assistance services or durable medical equipment, are critically important to some people with disabilities. For those who need them, these services are a lifeline to independence, living in the community, and employment. Either not affordable or available through the private insurance market, Medicaid has been the sole access point for people with disabilities who need long-term care services.

Those who are familiar with Medicaid, a program governed by specific guidelines defined by the federal government but implemented and managed at the state level, understand that there are many nuances and differences in the program across the country. The Adult ACA Medicaid group, or expansion group, is a Medicaid program that may or may not provide an individual with long-term care services in any given state.

Continuing our work with advocates and state policy makers across the country, HDA finds that people with disabilities are experiencing painful gaps in coverage and access to their providers and specialists in at least two circumstances: the first is those individuals, largely in 209(b) states that have expanded the Medicaid program, who apply but are not yet found eligible for SSI. The other is youth with disabilities who undergo a redetermination process at age 18 as they transition to the adult system.

209(b) Expansion States Facing Challenges with Transitions

One key difference across states is the state option to automatically provide SSI Related Medicaid to recipients of the federally-administered state supplementary payments though the Supplemental Security Income (SSI) program. SSI is a cash benefit program for which 33 states and the District of Columbia (called "1634 states") have chosen to match financial eligibility. For the individual, this means that if you apply and are found eligible for SSI, you are automatically eligible for Medicaid and long-term care services. For the state, this means that the federal determination of disability is adopted for state programs, and related data and policy infrastructure must be in place to coordinate between the Social Security Administration and state agencies. Seven additional states (called "SSI-criteria states") use the SSI eligibility criteria for Medicaid, but make their own Medicaid determinations, as opposed to adopting the federal determination.

The remaining ten states use at least one eligibility criterion that is more restrictive than the SSI program for Medicaid eligibility, and are referred to as "209(b) states." This means that an individual who applies and is found eligible for SSI must make a separate application for Medicaid coverage to the appropriate state agency.

209(b) STATES

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The following states are currently 209(b) states: Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma and Virginia. All but Missouri, Oklahoma and Virginia have expanded Medicaid eligibility through the ACA.

Limited Access to Long-Term Care and Providers in the ACA Adult Group

Because many SSI applications take longer to process than Medicaid applications, people with disabilities can frequently be found eligible for ACA Adult Medicaid while waiting for SSI eligibility to be approved. While this group of individuals who have been approved as ACA Adult Medicaid eligible does provide access to healthcare, it may not provide access to long term care services.

Once SSI eligibility is approved, however, the beneficiary is no longer eligible for the category of Medicaid (ACA Adult) they are currently receiving. When they are put into the correct category for coverage (SSI Related Medicaid), they are sometimes dropped from one health plan and put into another without their knowledge. The end result is a current Medicaid beneficiary who is denied or faces delayed access to long-term care services he or she should be receiving under SSI Related Medicaid, as well as potentially losing access to providers and being forced to reapply altogether.

In addition to the lack of access to needed long-term care services, the individuals may also experience challenges related to accessing medical service providers. In some states, the integration of the ACA and managed care has vastly changed provider infrastructure, with managed care plans for SSI Related Medicaid offering different provider networks and services than ACA Adult Medicaid managed care plans.

Joe had an application pending for SSI at the time he applied for Medicaid. He was approved for Medicaid under the new ACA Adult Medicaid category. After being approved for ACA Adult Medicaid, Joe was told that he needed to enroll in a managed care plan, and joined Harmony Health Plan.

Later on, Joe was also approved for SSI. As Joe was going through the redetermination process, his coverage was changed to SPD Medicaid (an SSI related eligibility category in Illinois) without his knowledge. He was kicked off of Harmony Health Plan because they don't serve SPD Medicaid. His established health care providers will no longer see him because he is no longer "eligible" for their services. Joe had no idea that his category of coverage had changed because he received no notice from the state. He turns to a local Aging and Disability Resource Center for help.

Many individuals, especially those new to SSI Related Medicaid, will not be aware that they are in a different category until another action is taken, such applying for a Medicaid waiver service, attempting to contact their managed care plan, or going to see their providers. Both of these issues can result from the timing of an individual's Medicaid application and approval.

Youth with Disabilities Facing Challenges with Transitions

Youth with disabilities can also potentially face significant unintended consequences around access to appropriate health care coverage. Children with disabilities are found eligible for SSI due to a reduction in both Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL). This means a youth can be eligible for SSI under a broader context of criteria, like an inability to socialize or play with others.

Adult disability determinations, by contrast, are made based on a disabling condition that impacts employment—not only current employment, *any* employment in the country that may be available to someone with such impairments. These are vastly different criteria.

As a result, many children are found eligible and begin receiving childhood SSI and SSI Related Medicaid; however, when they turn 18, they are required to meet the adult disability guidelines in order to remain eligible. Many children fail to meet those adult requirements and their benefits are terminated. However, of those that are found ineligible when they turn 18, a number are later found to be eligible in further review or appeal processes. This occurs for some children who participate in Medicaid waiver programs, which are available only to individuals who are current Medicaid recipients. Many of these waivers are restricted in their number and it can frequently take years for individuals to receive a waiver after being on a waiting list.

A case example of what can happen is provided on the following page.

Tara was diagnosed with autism when she was six years old. She was on a waiting list for three years to receive waiver services for assistance with IADLs, finally becoming eligible when she was nine. She has been receiving SSI and SSI Related Medicaid since she began school when she was five years old.

Tara turned 18 on June 6, 2014 and recently received an age-18 redetermination for adult SSI. Tara's application was denied and her eligibility for SSI, SSI Related Medicaid, and her waiver services were all terminated. Tara reapplied for both SSI and for SSI related Medicaid. Her SSI application was denied a second time, but her Medicaid eligibility was approved under the MAGI for healthcare coverage in the new adult group. Tara appealed the denial of the SSI and requested an ALJ appeal for SSI. Tara reapplied for waiver services, but was told they were not available under her coverage.

Tara's hearing with an Administrative Law Judge was held in January 2015, where she was found eligible for SSI under the adult determination. She received a note from her providers saying she was no longer eligible for services because her ACA related Medicaid was no longer available. After numerous phone calls, Tara's mother found out she could reapply for SSI Related Medicaid. Upon reapplication, her SSI Related Medicaid was approved and she was again eligible for services. She reapplied for waiver services and found eligible, but was then notified of the projected four-year waiting list.

As illustrated above, a child may have waited years to be eligible for Medicaid waivers, be found eligible, only later to be denied eligibility for adult disability--which results in losing benefits under SSI Related Medicaid and SSI eligibility. If, upon later application, the individual is once again found eligible for both adult SSI and SSI Related Medicaid, her or she must now go to the back of the waiting list for the same waiver services previously lost under a youth determination. This can result in years without necessary, critical services and care.

Experiences in the States

HDA conducted a short, informal survey of seven 209(b) states that have expanded Medicaid to learn more about how states identify people who are in the "wrong" eligibility category and the process controls states have in place to prevent this from happening.

With six of the seven states responding to our survey, we found that:

- Three of six respondents offer Medicaid provider packages that are different depending on whether you are in SSI Related Medicaid or ACA Related Medicaid.
- Three of the six responding states offer some variety of waivers to individuals even if they are placed in ACA Related Medicaid.
- None of the responding states have a formal process for coordinating information about individuals who transition eligibility from one service package to another. Minnesota identified this as an issue and is currently in the process of instituting a new data management system that helps coordinate and track transitioning beneficiaries.

- Four of six states are unaware of whether individuals have been improperly placed in the wrong Medicaid eligibility package; the remaining 33% have implemented trainings, but know that individuals continue to get placed into the wrong eligibility group.

- Five states (all but North Dakota) were not aware of specific alerts that notify the Medicaid beneficiary that their eligibility for one program has ended and another started. As the one state that does provide alerts, North Dakota survey respondents noted they were also aware that individuals have been impacted by being turned away from providers upon eligibility group changing..

Upon further contact, roughly half of the states were in the early stages of identifying the issue of individuals being inappropriately placed and noted a need to develop a process for re-engaging the beneficiary to get them connected to appropriate providers for maximized health. In some cases, like Connecticut, a process was developed to train enrollment and eligibility workers to identify the issues, yet the problem continues to exist. New Hampshire was examining an eligibility crosswalk to identify indicators of disability to ensure individuals are appropriately placed, but have not yet finalized and implemented procedures that would reduce the number of individuals placed in the incorrect eligibility group.

Individuals with disabilities who require access to long-term care and youth with disabilities in transition to the adult system are adversely impacted by incorrect placement in the ACA Adult Medicaid category and could be denied both medical services and services that allow community treatment for long-term care. Because many do not know what they don't know, the end result is a number of vulnerable individuals who are left trying to re-engage the Medicaid system to figure out what went wrong.

This has been confirmed based upon limited follow up with states and experientially from individuals seeking assistance to understand their individual cases.

Recommendations Going Forward

While states are currently uncertain about the scope and breadth of these issues, it is important to identify individuals who have fallen through the cracks and may experience a significant disruption in services and eligibility. At a minimum, it seems that requiring states to create an automated notification system for changes to eligibility would provide beneficiaries greater clarity and time to plan. In North Dakota, for example, individuals receive a notice as they leave eligibility under one Medicaid group and become eligible for another. Notice of and clear information about the ramifications of the change are critical.

Another recommendation for states is to look at integration of its systems and data tracking of disability populations. Data exchanges between the state and federal systems, along with the differing eligibility criteria among various programs, should make tracking persons with disabilities a high priority for states. Minnesota, for example, is developing a new integrated system with the capacity to match data sets to a broader context of information, such as employment status. This will greatly enhance the ability of the state to make sure that people with serious health needs receive the proper services and have access to the supports they need for the greatest possible independence.

Access to waivers for people with disabilities is another necessary area needing attention. Most states currently limit access to waivers, and the ones that allow for waivers provide primarily state-only funded waivers.

This means that the individuals who may apply for waivers are likely to be placed on an extended waiting list that provides no benefit until eligible, which can happen years down the road.

Recommendations for Immediate Action

1. The Center for Medicaid and CHIP services (CMCS) should issue a State Medicaid Director letter for states that have expanded ACA Adult Medicaid. The letter should highlight the problem of transition between eligibility categories for people with disabilities and require clear, concise notifications for both individual beneficiaries and providers. Communications for individuals enrolled in Medicaid and the Marketplace need to provide information at the point of annual redetermination and during changes in coverage categories. Recognizing the value of employment opportunities for people with disabilities, an emphasis on information about existing programs, such as the Medicaid Buy In program, should be included.

2. The State Medicaid Director letter should require protocols for notifications from managed care plans to beneficiaries, directing them to resources for help navigating transitions between eligibility categories.

3. CMCS should issue a State Medicaid Director letter to all states directing them to evaluate the challenges facing transition-age youth with disabilities as they transition coverage from childhood SSI to Adult SSI. No young adult should lose their access to critical Medicaid waiver services or be disadvantaged in any way during their transition between SSI categories.

FOR MORE INFORMATION


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