Office of Affordable Health Care

2023 Public Hearing Comment Solicitation – **Advocacy/ Professional Associations and Others**

*Written comments are due by midnight on Friday October 6th, 2023.*

*Comments may be emailed to* *meg.garratt-reed@maine.gov**, and should be attached as a word document or PDF. Please note that comments are not confidential and will be posted publicly.*

Submitter Information

Organization: Disability Rights Maine

Individual submitter’s name:

Title:

Comments

1. Please identify and briefly describe the top (2-3) cost-related barriers consumers in Maine face when attempting to access necessary health care.

Disability Rights Maine (DRM) is Maine's designated Protection and Advocacy (P&A) agency, a 501(c)3 organization authorized and mandated to protect and advocate for the rights of Maine people with disabilities. DRM's mission is to advance justice and equality by enforcing rights and expanding opportunities for people with disabilities in Maine.

Although people with disabilities face numerous cost-related barriers to care, DRM is focusing on two major barriers in these comments.

**Inability to afford out-of-pocket health care costs.**

Mainers with disabilities experience unique circumstances that result in an exceptional cost burden and significant negative impacts on accessing care. People with disabilities often require frequent medical visits, prescriptions, assistive devices, or home care services, resulting in higher out-of-pocket expenses. Serious economic disadvantages also profoundly impact the ability of people with disabilities to afford these higher costs. Those with disabilities are nearly three times more likely to live in poverty[[1]](#footnote-1) and experience twice the rate of unemployment.[[2]](#footnote-2) The median household income for people with disabilities is $36,000 compared to $62,000 for people without disabilities.

The resulting impacts on access to care are serious. Nationally, American adults with disabilities are twice as likely to report delaying a healthcare appointment or prescription refill because of cost, compared to their peers without disabilities.[[3]](#footnote-3) In a recent assessment by DRM of barriers to healthcare for people with disabilities, over half of survey respondents reported experiencing a need for health care but not getting it.[[4]](#footnote-4) Among these respondents, 21% said the reason was that the care was too expensive, or insurance did not cover the service.

In DRM’s recent assessment, participants with disabilities highlighted several specific issues contributing to high out-of-pocket costs.[[5]](#footnote-5) The high cost of prescription medications, in particular, meant that participants could not accept or purchase their medicine at times. Limited networks and appointment availability meant individuals needed to travel farther and more often to receive needed care. Transportation costs are a significant financial burden, especially for those who require specialized transportation services (e.g., wheelchair-accessible vans) or accommodations. Participants cited limitations on health services coverage as an issue, including the frequency at which certain services are covered. There was great frustration that standard health insurance plans did not include adequate coverage of dental, hearing, or vision services. Participants also raised concerns about a lack of transparency about cost and coverage of services on the part of insurance providers, specifically regarding treatments and diagnostic tests. Respondents indicated general hesitation to use health care services because a simple visit could be too expensive; even if a service is ultimately ‘covered’ by a plan, deductibles and cost-sharing requirements can still result in costs that only become clear after the service is provided, and which individuals simply cannot afford.

**Limitations in the MaineCare for Workers with Disabilities Program.**

It is essential that pathways to employment and higher incomes are kept open for people with disabilities, without negative impacts on their ability to access necessary health care or to afford its costs.

As noted above, people with disabilities often require ongoing access to certain services necessary to live independently in the community; for example, case management services, private duty nursing services, in-home support services, assistive technology, and others. Most of these services are simply not covered by private insurers. On a purely out-of-pocket basis, these services would result in such high costs as to be unaffordable to all except the highest income brackets. For the vast majority, the only available coverage option is through MaineCare, Maine’s state Medicaid program. As a needs based program, MaineCare has restrictive income and asset limitations.

When people with disabilities pursue employment and greater economic security, their need for these services to live independently does not cease. Nor do these services suddenly become available through other options. In recognition of this reality, MaineCare offers the MaineCare for Working People with Disabilities option. However, the design of this program, including unearned income caps and asset limitations, means that many people cannot use it as intended. This does not have to be the case. Maine could change the MaineCare for Workers with Disabilities option to encourage participation by more individuals. Better yet, insurance plans offered by Medicare and private insurers could be structured and designed to provide benefits that individuals with disabilities need to work and live independently.

1. Of the barriers described in question one, are there characteristics specific to Maine (geographically, economically, demographically) that contribute to the significance of the issue here?

Maine has a higher proportion of people with disabilities than the national average.[[6]](#footnote-6) From 2017 through 2021, just over 211,000 persons with one or more disabilities resided in Maine, equal to almost 16 percent of its civilian non-institutionalized population of 1.3 million.[[7]](#footnote-7) This proportion was higher than that of the United States, where an estimated 12.6 percent of residents had a disability.

In Maine, about half of residents with a disability are of working age (18 to 64 years).[[8]](#footnote-8)

One barrier specific to Maine is the structure of its MaineCare for Workers with Disabilities Program. As currently designed, this program provides MaineCare coverage to individuals under 65, who meet the Social Security Administration definition of disability, who have earned income as a result of employment or self-employment, and who meet the current income and asset parameters established. The program has a combined income limit of 250% of the Federal Poverty Level, and an asset limit of $8,000 if single and $12,000 if married. Perhaps most importantly, Maine has also chosen to adopt an *unearned* income limit equal to 100% of the FPL. Premiums begin if someone has an income above 150% of the FPL.[[9]](#footnote-9) This unearned income cap has significant impacts on the ability of individuals with disabilities to pursue employment. While there are many states that utilize a 250% FPL income test, few include as restrictive an unearned income cap as Maine. By eliminating the unearned income cap, more SSA Title II beneficiaries, in particular, will be able to access this form of MaineCare. This will mean more people are able to return to work, and work more, without risk of losing their health insurance, or more critically, the services that allow them to work and become more independent that Medicaid provides.

1. With as much specificity as possible, please identify and describe the top state health policy changes your organization would recommend reduce or eliminate these barriers.

**Remove the unearned income cap for the MaineCare for Workers with Disabilities Program.**

We recommend that Maine review the structure and design of the MaineCare for Workers with Disabilities program so that more Maine people with disabilities are able to work to their full potential and maintain access to the health care and health insurance they need. This will help more Mainers start and return to work, and will help workers stay in the workforce past age 65, all of which are critical to Maine’s current workforce needs. While work on this policy will require approval from CMS, it does not require any changes at the federal level.

This Medicaid eligibility option became available in Maine in August of 1999 and was enacted under authority established by the Balanced Budget Act (BBA) of 1997.[[10]](#footnote-10) Later in 1999, the Ticket to Work and Work Incentives Improvement Act (TWWIIA) of 1999 was enacted, which gave state Medicaid offices further authority to expand their programs for workers with disabilities to more groups. The BBA governs the Work Incentives Group, while the TWWIIA governs the Ticket to Work Basic Group and the Ticket to Work Medical Improvements Group.[[11]](#footnote-11)

By utilizing the authority of the BBA, and by using state authority to include an unearned income cap of 100% of the FPL[[12]](#footnote-12), Maine restricted access to this program. Maine could, and should eliminate the unearned income cap to this program as a first step in improving access to health care and increasing employment levels of people with disabilities. **While there are many states that utilize a 250% FPL income test, few include as restrictive an unearned income cap as Maine.**

Beyond that, Maine could dispel with the current age cutoff of the program, and change or eliminate in its entirety income and asset limits utilizing layered authority under the BBA and TWWIIA, while also reducing the impact of spousal income counting.

Many other states, like Colorado and Maryland, are undergoing changes to expand their Medicaid Buy-In programs so that more disabled workers are able to keep their health insurance and work more. As an early adopter of this program and a leader in the Employment First movement, Maine must make changes to this program to continue to support the employment of Mainers with disabilities.

For more information regarding policy implications and planning, we recommend the following resources:

[Next Steps: Improving the Medicaid Buy-in for Workers with Disabilities,](https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2022/12/BPC_Health-MBI-Report_RV4.pdf) December 2022, Bipartisan Policy Center

[Medicaid Buy-in Q&A](https://www.dol.gov/sites/dolgov/files/odep/topics/medicaidbuyinqaf.pdf)

[Medicaid Eligibility through Buy-In Programs for Working People with Disabilities](https://www.kff.org/other/state-indicator/medicaid-eligibility-through-buy-in-programs-for-working-people-with-disabilities/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D#note-3), Kaiser Family Foundation

**Explore Options for Promoting Equitable Benefit Design of Private Health Insurance Plans.**

For better or worse, the structure for payment of health care services in the United States is based on third-party payers, either through private insurance or through public insurance programs. Health care services are so costly that it is not feasible to assume that those without a third-party payer can afford to pay out of pocket. This is particularly true for people with disabilities.

Purchasing individual private insurance is rarely an option for people with disabilities. In addition to the affordability of premiums, plans often do not provide adequate benefits for people with disabilities, because they are crafted to cover basic care required by average working populations with fewer health care needs. In order to live independently in the community, many people with disabilities require specialized and on-going community-based services such as case management, care coordination, assistive technology, personal assistance, and other home- and community-based services, which private insurance plans generally do not cover. Private insurance plans also do not reimburse providers for sign language interpreters or cover the cost of vision rehabilitation for people who are blind or who have vision impairments. Nor do payment structures account for the need for longer appointments or modifications in processes or equipment necessary to ensure equitable access and quality of care received by people with disabilities. This is a significant cost barrier to care that merits attention and policy consideration, particularly in light of the large numbers of people with disabilities in Maine.

1. Please share any additional comments.
1. US Census Bureau American Community Survey, 2017-2021 5-Year Estimates. [↑](#footnote-ref-1)
2. Maine Dept. of Labor, “Maine Workers with Disabilities 2021 Data Update.” <https://www.maine.gov/labor/cwri/data/disabilities/maine_workers_with_disabilities.docx> [↑](#footnote-ref-2)
3. Centers for Disease Control and Prevention, "Disability Barriers," <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>. [↑](#footnote-ref-3)
4. Disability Rights Maine, “ ‘I Don’t Get the Care I Need:’ Equitable Access to Health Care for Mainers with Disabilities.” <https://drme.org/assets/brochures/DRM-Equitable-Access-to-Health-Care-for-Mainers-with-Disabilities-Final.pdf> [↑](#footnote-ref-4)
5. Ibid [↑](#footnote-ref-5)
6. Maine Dept. of Labor, “Maine Workers with Disabilities 2021 Data Update.” <https://www.maine.gov/labor/cwri/data/disabilities/maine_workers_with_disabilities.docx> [↑](#footnote-ref-6)
7. Ibid. [↑](#footnote-ref-7)
8. Ibid. [↑](#footnote-ref-8)
9. Medicaid Eligibility through Buy-In Programs for Working People with Disabilities, 2022. <https://www.kff.org/other/state-indicator/medicaid-eligibility-through-buy-in-programs-for-working-people-with-disabilities/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> [↑](#footnote-ref-9)
10. <https://digitalcommons.usm.maine.edu/cgi/viewcontent.cgi?article=1094&context=aging> pg 4 [↑](#footnote-ref-10)
11. <https://bipartisanpolicy.org/download/?file=/wp-content/uploads/2022/12/BPC_Health-MBI-Report_RV4.pdf> apendix A - page 53. [↑](#footnote-ref-11)
12. [https://aspe.hhs.gov/sites/default/files/migrated\_legacy\_files//40351/Eilesson.pdf](https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/40351/Eilesson.pdf) page 18 [↑](#footnote-ref-12)