



BRIEF

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Addressing the benefits cliff to enable equitable compensation for consumers

Recommendations for policymakers and organizational leaders

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Background: How community and consumer engagement programs run into the benefits cliff problem

It is vital for health and social care organizations to partner with people with lived experience¹ to inform the design and operation of their programs. Consumers and people with lived experience of the health or social needs being addressed by these organizations have unique wisdom, insights, and deep understanding of the needs and assets of their communities. All of these are necessary to ensure programs meet community needs and achieve their desired outcomes.

Health and social care organizations are increasingly working with people with lived experience in a number of ways including (but not limited to): inviting individuals to share their stories, collecting feedback through surveys and focus groups, and including people with lived experience on advisory boards, working groups, and organizational governance.

Partnerships between healthcare and social service organizations and their communities and consumers must be built on a foundation of trust, equity, and mutual benefit. Organizations are increasingly recognizing that paying people fairly for their work is essential to equity and inclusion, and are moving to financially compensate people with lived experience for their input, advice, leadership, and advocacy.

However, many people with lived experience of medical and social complexities receive supports through public benefit programs such as Supplemental Security Income (SSI), SNAP (food stamps), TANF (cash assistance), Medicaid, childcare subsidies, and public housing.

Each of these public benefit programs imposes limits on the income and financial resources that benefit recipients can receive before becoming ineligible and losing their benefits. This is known as the “[benefits cliff](#).” The benefits cliff has been a longstanding challenge for recipients of public benefits, and presents a unique challenge to people with lived experience who do work as consumer/patient advisors and advocates.

¹ In this document we use the terms “people with lived experience” and “consumers” interchangeably to refer to people who are the end users of our health and social care systems. We recognize that these terms come with some limitations and not everyone prefers to identify as such.

What can healthcare and social service organizations do to fairly compensate people with lived experience who receive public benefits?

As healthcare and social service organizations expand their partnership work with people with lived experience, especially individuals from historically underrepresented communities, challenges arise in how to fairly compensate individuals who receive public benefits.

Too often, outdated public benefits eligibility rules and rigid income and resource limits prevent people with lived experience from accepting payment for their essential work improving our systems of care. These rules put people in an unjust position to decide between working for free, or risk losing the life-sustaining public benefits they rely on.

Ultimately, policy changes are needed to ensure that public benefit recipients are afforded the opportunity to do work that aligns with their abilities, interests, and goals — as well as to live financially secure lives. We outline a number of these policy recommendations below.

Organizations that partner with people with lived experience in their work have a responsibility to champion these policy changes, but we recognize that these policy changes will not be easy to achieve. In the meantime, organizations should **adopt compensation practices that are responsive to the needs of benefit recipients.**

Policy changes are needed to ensure that public benefit recipients are afforded the opportunity to do work that aligns with their abilities, interests, and goals.

Best practices for compensating consumers

1. Don't assume all consumers are public benefit recipients, or that they cannot accept supplemental income.
2. Offer to break up larger sums into smaller payments over time.
3. Be mindful of the potential impact of gift card payments.
4. Connect consumers to community-based resources that can provide benefits counseling.
5. Offer compensation other than monetary payments for consumers who cannot accept supplemental income.

Learn more at camdenhealth.org/compensating-consumers



KATIE'S STORY

In my role as a Peer and Family Specialist, I mentor others experiencing homelessness, substance abuse, behavioral health issues, and addiction. I currently serve in leadership roles with several state and community organizations.

But as an SSDI recipient, I am limited in how many hours I can work without jeopardizing my benefits. Not only is it difficult to try to understand and navigate this system, but many times it has prevented me from doing the work I love.

Recently, I was offered a wonderful job opportunity with a social service organization in Denver as a Certified Peer Specialist. This role would have been a perfect fit for me, but I had to turn down the opportunity. The reason? Because they could not accommodate the very part-time schedule that I need as a result of receiving SSDI. Unfortunately, this is not the only time this has happened to me.

The rules that are in place now set people up to fail, rather than support people to live their best lives.

I am grateful for every day for the work that I am able to do, however, we need policy solutions that eliminate the detrimental effect of the benefits cliff so more people like me and healthcare organizations can work together to foster well-being for ourselves and our communities.

Policy recommendations to address the benefits cliff

Ensure public benefit limits and allotments reflect the actual cost of living

Public benefit programs on their own are largely insufficient to meet the actual cost of living. As of 2022, a recipient of Supplemental Security Income (SSI) receives \$841 per month, while in New Jersey, the estimated livable income is over \$3000 per month.

Many public benefit programs base eligibility guidelines on the Federal Poverty Level (FPL), also called the Federal Poverty Guideline. This measure, with origins in the 1960s as part of President Johnson's "War on Poverty," was developed based on a limited scope of financial need. Many researchers, policymakers, and people who have lived experience of poverty agree that the official measure is flawed.² While the FPL is routinely updated to account for inflation, it has never been updated to account for the actual cost of living, and its methodological weaknesses have never been addressed.

Increasing public benefit eligibility limits and allotments to align with the actual cost of living is perhaps the most effective solution to eliminating the negative impact of the benefits cliff — but it is also a long-term and lofty aim.

According to the National Council of State Legislators, "one of the first steps in addressing benefits cliffs is to understand where and how they happen."³ To this end, tools such as the Self Sufficiency Standard and benefits calculators can help policymakers, caseworkers, and families better understand the impact of the benefits cliff.

Policymakers can also use the Self Sufficiency Standard to assess where, how, and to what degree current public benefit limits and allotments fall short, and to strategically direct resources to address these gaps.

2 U.S. Department of Agriculture, "SNAP Eligibility"; and U.S. Department of Agriculture, "WIC Eligibility Requirements."

3 *Addressing Benefits Cliffs*. (n.d.). Retrieved October 27, 2022, from <https://www.ncsl.org/research/human-services/addressing-benefits-cliffs.aspx>

Streamline eligibility criteria across state and federal programs

Aligning eligibility requirements and income limits across state and federal public benefit programs would also help dismantle the benefits cliff. Benefits such as SNAP, TANF (cash assistance), Medicaid, childcare subsidies, and public housing programs all have income and asset limits and eligibility calculations that vary by program.

The complexity of these different eligibility systems makes it nearly impossible for the average person to understand how supplemental income could impact their public benefits eligibility or allotments. A 2017 Government Accountability Office report lays out steps that states can take to streamline program administration and rules, including better data-sharing.⁴

While alignment does not address the issue of adequacy, simplifying eligibility criteria within and across public benefit programs does foster greater transparency and allows individuals to make informed decisions about receiving supplemental income.

Expand access to tax-free savings accounts

Expanding awareness, access, and utilization of ABLÉ accounts, escrow accounts, and Individual Development Accounts (IDAs) is an effective and feasible policy option.

ABLE accounts are tax-free savings accounts that allow individuals with disabilities and their families to establish savings that do not affect eligibility for many public benefit programs. ABLE accounts are meant to supplement, not replace benefits, and account holders can use the funds for certain “qualified disability expenses,” which can, under some circumstances, include things such as food, housing, and transportation.⁵

Escrow accounts like the **Family Self-Sufficiency** (FSS) program allow HUD-assisted families to build a savings account without losing means-based housing assistance.

KYLE'S STORY



I have cerebral palsy. I am an athlete. I am a brother. I am a disabled individual. Me and my older brother, Brent, started the Kyle Pease Foundation, which allows individuals with disabilities to participate in sports.

I am on a Medicaid waiver in Georgia that allows me to hire my own caregivers. I am very grateful for the opportunity, and the people I have met through the waiver have changed my life. I am eternally grateful for my team that helps me get through the day.

However, that is where the benefits stop for me. Because I work, I don't get many other benefits besides the Medicaid waiver. In Georgia, there are some deficiencies in state policy that penalize people like myself for working. I have had to turn down many raises, many bonuses so that I can sustain my eligibility to live an independent life and my new independent apartment.

But that does not stop me. I want to live a full life and I want to work and show people what is possible.

My call to action is that we need to look at everybody and their unique situation, and figure out how we can make these benefits better for each person that signs up for them, whether they choose to work or not.

⁴ FEDERAL LOW INCOME PROGRAMS Eligibility and Benefits Differ for Selected Programs Due to Complex and Varied Rules. (2007). In gao.gov (GAO-17-558). <https://www.gao.gov/assets/gao-17-558.pdf>

⁵ What are ABLE Accounts? (2022, March 15). ABLE National Resource Center. <https://www.ablenrc.org/what-is-able/what-are-able-accounts/>



NAOMI'S STORY

I am the proud parent of Noah Williams. Noah is a minor, he is medically fragile and complex, and comes with a lot of social needs as well. As his mom, his benefits are based on my income, and so I had to limit my income in order for him to maintain his medical benefits.

Part of what I do is work as a consultant, an advocate, and a patient advisor, sharing our lived experiences and how policy and procedures truly impact us. When I have been approached about speaking engagements, I have had to choose whether to turn them down or to accept them. If I accepted them, at times that would put us over that threshold and my son would lose his benefits. If I declined them, that impacted our income.

If my son loses his medical insurance, I will never make enough money to support his care. Figuring out the dance of how to minimize my earnings or income potential to maintain his medical insurance, while working to give us a good quality of life, has been challenging, daunting, and exhausting.

I'm sharing my story with the hope of changing these policies. Policies like the income thresholds haven't been changed in 30 years. That's a long time. When we talk about the benefits cliff, there are so many pieces to this puzzle, and so many of us have had to figure out this dance, but those who have put the policies and procedures in place have never lived it.

State-supported IDAs are accounts that provide match funds or other incentives to help low- and moderate-income households grow their resources. In addition to providing an incentive to save, these accounts can be excluded as countable assets for public benefit programs, which ensures households are not penalized for saving.⁶

The opportunity to strengthen the impact of ABLE, IDA, and escrow accounts is two-fold. First, more states can adopt and support access to these programs. Secondly, policymakers can focus on providing outreach and enrollment support to ensure that individuals who are eligible for these types of accounts are aware of the programs and have the support they need to open and use them.

Exclude income earned from consumer work from eligibility calculations

Finally, it is possible to enact policies to disregard certain types of income in the calculations of eligibility for public benefits. This can include disregard for income earned through service-oriented work. For instance, stipends received through AmeriCorps programs are excluded when calculating eligibility for many state and federal benefit programs.⁷ Many states exclude income from temporary employment, such as census outreach work.⁸ Payment for participation in clinical trials are similarly excluded from income for SSI eligibility determinations.⁹

Policies to disregard income earned by people with lived experience who do work as consumer/patient advisors and advocates would be a significant step forward in advancing equity.

6 SSA - POMS: SI 00830.670 - Individual Development Accounts (IDAs) — Demonstration Project - 06/18/2001. (2001, June 18). <https://secure.ssa.gov/poms.nsf/lnx/0500830670>

7 <https://secure.ssa.gov/poms.nsf/lnx/0500830537>

8 State Exemptions and Waivers for Temporary Census Workers Who Receive State Benefits. (n.d.). Retrieved October 27, 2022, from <https://www.ncsl.org/research/redistricting/state-exemptions-and-waivers-for-temporary-census-workers-who-receive-state-benefits637160804.aspx>

9 SSA - POMS: SI 00830.735 - Payments for Clinical Trial Participation - 10/15/2015. (2015, October 15). <https://secure.ssa.gov/apps10/poms.nsf/lnx/0500830735>



Summary of recommendations:

Healthcare and social service organizations that partner with people with lived experience should:

- ▶ [Educate themselves about this issue](#),
- ▶ Provide flexible compensation options, and
- ▶ Help people connect to resources as needed.

Policymakers should:

- ▶ Apply income disregards across federal and state benefit programs to exclude income from work done by people with lived experience who do work as consumer/patient advisors/advocates.
- ▶ Align, simplify, and ultimately increase state and federal program eligibility guidelines.

Organizations and policymakers should:

- ▶ Use tools such as the Self Sufficiency Standard and Benefits Calculator to routinely assess the (in)adequacy of public benefit allotments, strategically direct resources to fill gaps, and to support individuals in understanding the impact of supplemental income on their public benefits.
- ▶ Work to improve awareness about, access to, and utilization of ABLE, escrow, and Individual Development Accounts.

Thank you to Katie Broeren, Kyle Pease, and Naomi Williams for contributing their stories.

In memoriam: Katie Broeren, co-author of this brief, passed away before the brief was published. Her life and work will continue to be a guiding light for the Camden Coalition and the work of the complex care field.

About the Camden Coalition

We are a multidisciplinary nonprofit working to improve care for people with complex health and social needs in Camden, NJ, and across the country. The Camden Coalition works to advance the field of complex care by implementing person-centered programs and piloting new models that address chronic illness and social barriers to health and wellbeing. Supported by a robust data infrastructure, cross-sector convening, and shared learning, our community-based programs deliver better care to the most vulnerable individuals in Camden and regionally.

Through our National Center for Complex Health and Social Needs (National Center), the Camden Coalition works to build the field of complex care by inspiring people to join the complex care community, connecting complex care practitioners with each other, and supporting the field with tools and resources that move the field of complex care forward. The National Center's founding sponsors are the Atlantic Philanthropies, the Robert Wood Johnson Foundation, and AARP.



**Camden
Coalition**



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