



July 27, 2021

Compensating consumers and considerations for public benefit recipients

How organizations can fairly compensate lived-experience experts without jeopardizing their eligibility for federal or state benefits

As lived-experience experts, consumers serve an invaluable role in informing policy and programming among non-profit organizations. Yet, as recognition of the importance of consumer contributions grows, organizations continue to struggle with compensating participants in a fair and equitable manner. Compensation disparities between consumers and other consulting experts can leave consumers feeling unappreciated and undervalued in their roles; it can also contribute to wage and income disparities that have persisted for too long. Organizations therefore have an obligation to address these disparities — both by working within the current legal confines as well as advocating for improved opportunities for compensating all consumer experts.

One major challenge in compensating consumers is the looming concern of lost public benefits. Many people living with complex health and social needs receive federal and/or state benefits such as Supplemental Security Income (SSI), SNAP, Medicaid, and subsidized housing. For those individuals, receiving or retaining additional income can jeopardize benefit eligibility. Disability rights and public benefits advocates refer to this as the “**benefits cliff**”. Often talked about in relation to “low-wage” workers, the “benefits cliff” presents a significant barrier to fairly compensating many individuals with lived experiences who engage in work as consumer advocates and advisors.

For example, SSI recipients face diminished monthly benefits following any month where they receive over \$85 of countable income. In addition, individuals with over \$2,000 in assets become ineligible for SSI. Thus, consumers receiving SSI can be penalized for both receiving and **accruing funds**. Consumers receiving SNAP, Medicaid, housing, and other benefits face similar income and asset limitations that disincentivize the creation of even minimal savings.

Given current governmental constraints, organizations can take the following steps to compensate consumers fairly, while reducing the likelihood of jeopardizing eligibility for critical benefits:

- **Don't assume all consumers are public benefit recipients, or that they cannot accept supplemental income.** Instead, have open conversations with consumers about the potential impact of supplemental income on their public benefits and provide flexibility and additional educational/support services based on each individual's circumstances.
- **Offer to break up larger sums into smaller payments over time.** Proactively ask consumers how much supplemental income they can accept in a given month or year, and alter compensation amounts accordingly. As noted, for SSI recipients, annual income of \$1,000 divided into monthly payments should not impact those benefits, provided consumers are not accruing savings.
- **Be mindful of the potential impact of gift card payments.** Any gift card that can be converted into cash or used to pay for food or shelter is technically income that is countable by the **Social Security Administration** and can jeopardize benefits eligibility. However, rules for if/how gift cards are counted for other benefits vary — for instance, **SNAP rules** state that gift cards issued by financial companies (e.g., VISA, American Express, etc.) are countable income, but establishment specific gift cards (e.g., an Amazon gift card) are excluded in income and asset calculations. Although gift cards are less likely to be detected by agencies monitoring benefits eligibility, there are risks for consumers who are receiving benefits and accept gift card payments. If detected, gift cards (or countable assets acquired with gift card proceeds) can still negatively impact someone's eligibility. In addition, consumers can incur overpayment penalties — and potentially even criminal charges — for failing to report income to applicable federal and state agencies. Many consumers are unaware that gift card payments are considered countable income for certain benefit programs, so it is important for organizations to ensure that consumers who choose to accept money in this way are aware that these payments may still be countable towards benefits eligibility and may need to be reported.
- **Connect consumers to community-based resources that can provide benefits counseling to help them understand how supplemental income will impact their benefits.** This type of assistance is not readily available in every community, so organizations should do more than simply provide a referral to a local agency. Start asking your local **Ticket to Work** provider if they offer **benefits counseling**, or contact your local **Work Incentives Planning & Assistance (WIPA) Projects** provider. Consumers can also be directed to call the national Ticket to Work helpline at 866-968-7842 and ask to be connected to a WIPA provider near them.
- **Offer compensation other than monetary payments for consumers who cannot accept supplemental income.** This could include covering the cost of them attending a professional conference or training that is of interest to them, or offering to donate their stipend directly to an organization or charity on their behalf. It is important that organizations build authentic relationships with consumers

to understand their interests and motivations for engaging in consumer work to ensure that alternative compensation is truly of value to them.

In addition, organizations must **advocate** for federal and state public benefits policy changes to end the detrimental impact of the “benefits cliff” and encourage equitable compensation for consumers. The federal government already recognizes the concept of excluding income for consumer advocacy and volunteer work. For

example, the Social Security Administration (SSA) excludes from income AmeriCorps and National Civilian Community Corps (NCCC) payments, as well as compensation to volunteers from the Corporation for National and Community Service (formerly known as ACTION) programs run by state and local subdivisions. The SSA also excludes \$2,000 in annual income from clinical trials. At a minimum, organizations must work to broaden these exclusions to cover additional consumer work by benefit recipients.

Additional resources for compensating consumers:

- **Building authentic and mutually beneficial partnerships with complex care consumers | Playbook**
- **Considerations for self-advocates receiving government benefits**
- **Engaging people with lived/living experience**

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