

Compensation Considerations for Self-Advocates Receiving Government Benefits

Tip Sheet
April 2018

People with disabilities are integral voices in the movement to end the violence that they experience. Paying people with disabilities for their work and involvement in these efforts is critical to ensuring equal justice and opportunity for all involved.

Some people with disabilities receive means-tested or income-based benefits through government programs. Recipients must prove that their income is below a set level to be eligible. As a result, it is critical that they and the organizations that compensate them for their work are aware of how consultant fees, stipends, gift cards, and other forms of compensation may affect their eligibility for government benefits.

The eligibility rules for government programs that provide benefits for people with disabilities are complicated. They sometimes restrict how much a recipient can earn. Nevertheless, there are many available resources—known as “employment supports” or “work incentives”—for people with disabilities

How to use this tip sheet

This tip sheet gives basic information on some government means-tested benefits programs for people with disabilities and explains the potential effects that receiving compensation may have on their benefits. It also guides readers to additional resources for people with disabilities and their advocates. Please note that the tip sheet is for general informational purposes only and does not, nor is it intended to, constitute legal advice.

For more detailed information on benefits-related programs, contact the resources in the final section or consult with an attorney.

Legal aid organizations in your state, or your state’s protection and advocacy agency, should have attorneys who are experienced in federal and state benefits law and can apply the law to your specific circumstances.

who want to be involved in efforts to end violence against people with disabilities and to receive compensation for their work. The information in this tip sheet can help people with disabilities to decide what work they can do while retaining the benefits they rely on for daily living.

Compensation methods

There are various ways that organizations and collaborations compensate people with disabilities for their involvement, time, and participation. Some of the types of compensation that might affect means-tested benefits include:

- › hourly wages, consultant fees, stipends, and honoraria (given as cash or by check);
- › gift cards;
- › travel tickets (for example, bus tickets, train tickets, or airplane tickets);
- › reimbursement for travel expenses (for example, getting reimbursed for what a self-advocate spends on transportation, food, and lodging); and,
- › per-diem reimbursement for food and incidental expenses (a set daily sum for food and other expenses, regardless of what a person spends).

Federal and state income-based programs

Many of the public benefits and programs that people with disabilities rely on—such as those that assist with housing, health care, and money for food and other living expenses—require recipients to report any earnings. Many people with disabilities are enrolled in more than one of these programs. Organizations that plan to compensate people with disabilities thus must consider how compensation may affect each of the programs in which self-advocates participate. Below are descriptions of the benefits programs that people with disabilities most frequently rely upon and guidance on potential concerns regarding compensation.

Monthly income-support programs

Supplemental Security Income (SSI) perma.cc/W6W2-X9UT

SSI is a federal income supplement program designed to help aged, blind, and people with disabilities who have little or no income. Based on both disability and financial need, SSI provides cash benefits to meet basic needs for

food, clothing, and shelter. In order to qualify for SSI benefits, a person can have no more than \$2,000 in savings/resources; a family can have no more than \$3,000 in savings/resources.

A person's primary residence, primary vehicle, ABLE account (tax-advantaged savings accounts for people with disabilities and their families) (perma.cc/9H9J-XAPY) balances, and other resources do not affect SSI eligibility, nor does it matter whether or not the person worked and paid into the Social Security system.

Social Security Disability Insurance (SSDI) perma.cc/5LAK-T8CB

This federal program pays benefits to individuals and certain members of the individual's family if that person is "insured," meaning that he or she worked long enough and paid sufficient Social Security taxes to become eligible for cash benefits. Unlike the other programs described here, SSDI benefits are based on a person's earnings from employment and what they paid into the program.

In order to qualify for SSDI, a person needs to have worked for a minimum amount of time depending on age when he or she becomes disabled; the benefit amount depends on the person's income history and work duration. People on

SSDI qualify for Medicare after two years. Disabled adult children and disabled spouses can sometimes receive SSDI benefits as well.

Income as defined by SSI/SSDI

SSI and SSDI have separate income requirements and standards. However, as a baseline, it is important to understand what is considered income.

Earned income – money earned for performing work. Limited if the person is on either SSI or SSDI.

Unearned income – payments from such sources as Social Security, veteran's benefits, a pension, alimony, investments, or child support; limited under SSI.

In-kind income – any type of free rent/shelter or food benefits from a nongovernmental source. For example, if you are allowed to live rent-free with a friend or your parents, this will be considered income (equal to earning the amount of money you would otherwise have to pay for the food, rent, and life necessities being provided to you). This includes gift cards.

Deemed income – a portion of income earned by other people in your house (for example, your spouse). This is called "deemed" income, because it is assumed

that a portion of this money will go toward your care and upkeep.

For SSI, earned income is counted as income after the first \$65 per month. Half of any earned money over \$65 per month counts as earned income. Unearned income is counted as income after the first \$20. Income above these amounts would decrease the monthly benefit payment dollar-for-dollar for the month of the income after the maximum allowed by the benefits program is met. If the income increase is sustained, it could affect eligibility unless the person enrolls in a work program.

What is not income under SSI and SSDI? perma.cc/YV5T-TTHD

Expense reimbursement is not considered income. Advances or reimbursements paid specifically for traveling or for other ordinary and necessary expenses incurred in the employer's business are not wages. The employer must identify travel and other expenses either by making a separate payment or by specifically stating the separate amounts if both wages and expense allowances are combined in a single payment.

Per diem is not considered income (usually). As long as the per diem paid is not above the government rate, it is not

considered income by the Social Security Administration (SSA). Anything above the government per diem rate is considered income.

Income limits for SSI

The federal benefit rate (FBR) perma.cc/WU2U-GWUJ represents both the SSI monthly income limit and the maximum federal monthly SSI payment (www.ssa.gov/oact/cola/SSI.html). The 2018 FBR for SSI recipients is \$750 per month for an eligible person and \$1,125 per month for an eligible couple. This amount includes the SSI payment itself. If a person gets the maximum FBR, any additional income could adversely affect their benefits.

Substantial gainful activity (SGA) under SSDI

To be eligible for SSDI benefits, a person must be unable to engage in substantial gainful activity. The SSA uses the term "substantial gainful activity" to describe a level of work activity and earnings. According to SSA rules, work is substantial if it involves significant and productive duties and pays more than the SSA's current monthly income limit. For work to be substantial, it does not need to be performed on a full-time basis. Gainful work activity is work performed for pay or profit; or of a nature generally performed

for pay or profit; or intended for profit, whether or not a profit is realized.

The SSA uses what are called “earnings guidelines” perma.cc/N3VZ-D6X4 to evaluate whether a person’s work activity is considered SGA for purposes of SSDI. The amount of monthly earnings the SSA considers to be SGA depends on the nature of a person’s disability:

- › If a person’s disability is anything other than blindness, earnings averaging over \$1,180 a month (for the year 2018) generally demonstrate SGA for SSDI recipients.
- › If a person is blind, earnings averaging over \$1,970 a month (for the year 2018) generally demonstrate SGA for SSDI recipients.

This amount includes the SSDI payment itself. Unearned income, from real estate or investments, for example, is not factored into income for SSDI purposes.

There are programs designed to encourage people on SSI and SSDI to return to work. If you or someone you know is interested in exploring these programs, see “Finding Answers to Your Questions,” page 10.

Housing

Public housing can also be affected by income. Programs administered by the U.S. Department of Housing and Urban Development (HUD) that seek to provide affordable housing for people with disabilities include:

Section 811 (Supportive Housing for Persons with Disabilities Program)

perma.cc/NY3Z-XZ7A

This program provides affordable, accessible housing for non-elderly, very low-income people with significant disabilities. It is typically integrated into larger affordable housing apartment buildings and is linked with voluntary supports and services. Tenants pay 30 percent of their adjusted income for rent, which ensures affordability for people who receive SSI.

Housing Choice Voucher Program (Section 8)

This is HUD’s primary program for helping very low-income families, the elderly, and people with disabilities to afford decent, safe housing in the private market. (perma.cc/2M4T-YP6C) About one in three households using Section 8 vouchers is headed by a non-elderly (under age 62) person with a disability. Tenants must be low-income, and typically pay 30 percent

of their income for rent. Participants must find their own housing, but they can choose any housing that meets the program's requirements. As a result of limited funding and high demand, most parts of the country have long waiting lists for Section 8 vouchers.

Public Housing

perma.cc/TF9R-PV2X

About one in five households living in public housing are headed by a nonelderly (under age 62) person with a disability. Tenants must be low-income, and typically pay 30 percent of their income for rent. As with Section 8 vouchers, availability is limited, and applicants may be on waiting lists for years.

Income limits for housing programs

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The maximum income that a person can earn and still qualify for a government housing program depends on location. Income determines not only eligibility, but also what a person's rent will be. HUD sets lower-income limits at 80 percent and very low-income limits at 50 percent of the median income for the county or metropolitan area in which a person chooses to live. Because rent is based on income, an increase in income can

affect not only housing eligibility but also rental rates within the program. A person can, therefore, continue to be eligible but experience an increase in rent because of additional income.

HUD measures income on an annual basis, and participants in these housing programs are required to project their income for the entire year. A local public housing agency makes the income determination at the time of the application, and the agency will reevaluate it each year thereafter.

What HUD considers income

perma.cc/FB7X-NMEE

- > all amounts, monetary or not, that go to the family that aren't otherwise not considered income
- > money received on a regular, reoccurring basis (monthly, weekly, etc.)
- > some welfare assistance payments
- > reoccurring disability payments (SSI, SSDI).

What HUD excludes from income

- > amounts received by a family that are specifically for, or in reimbursement of, the cost of medical expenses

- › temporary, nonrecurring, or sporadic income (including gifts)

Note: HUD regulations do not define temporary, nonrecurring, or sporadic income. Each situation is different, and the person evaluating someone for eligibility would make the final decision in the case.

HUD determines income based on very specific calculations of the number of family members, earned money, unearned money, geographic location, and housing costs. To get the correct information on eligibility and income calculation for these programs, speak to a legal aid organization, a housing advocate, or a housing agency.

Medicaid

This joint federal and state program helps with medical costs and insurance for some people with limited income and resources. It also offers such benefits as nursing home care and personal care services. Each state sets its own Medicaid eligibility rules. In some states, anyone on SSI qualifies for Medicaid. In others, applicants face income restrictions. A person whose income exceeds the state's limit typically will need to purchase insurance from the insurance marketplace to maintain coverage; in some states,

people can apply for “medically needy” status. The SSA generally calculates income for people who qualify for Medicaid because of disability in the same way it does for the purposes of assessing eligibility for SSI perma.cc/SK78-WZSF.

Medicare

This federal health insurance program is for people who are 65 or older, certain younger people with disabilities (those on SSDI), and people with end-stage renal disease.

Supplemental Nutrition Assistance Program (SNAP) and Supplemental Nutrition Assistance Program – Education (SNAP-Ed)

Formerly known as food stamps, SNAP is a federal nutrition program that helps eligible low-income individuals and families augment their food budget. SNAP-Ed offers education programs on nutrition and obesity.

Health Insurance Marketplace subsidies

The federal Affordable Care Act (also known as Obamacare) established health coverage available at reduced or no cost for people with incomes below certain income levels. In all states, household

income must be between 100 percent and 400 percent of the federal poverty level to qualify for a tax credit on health insurance premiums.

Low Income Home Energy Assistance Program (LIHEAP)

perma.cc/DAN2-K4ZH

This program assists eligible low-income families with energy costs, such as electric and gas bills.

Examples of compensation considerations

The examples below are hypothetical cases based on a thorough review of the regulations and rules. When reading them, assume that the person is not participating in a work-incentive program. In actual cases, program administrators analyze a variety of financial, medical, and other factors to determine eligibility. This is not legal advice and is not representative of what a Social Security administrator may decide in an individual case after a review of the facts.

Example A

Mattie participates in a collaboration's self-advocate advisory committee. This advisory committee meets in person

every other month, or six times a year. As compensation for her participation, Mattie receives:

- > a \$50 stipend or honorarium for each advisory committee meeting she attends,
- > a daily per diem of \$25 to cover her meals (breakfast and lunch), and
- > reimbursement for travel-related costs to attend the meeting.

Potential impact: SSI

Per diem and reimbursement for actual travel-related costs are not considered income by SSA. The \$50 stipend is earned income. However, since it is less than \$65 per month, it will not be counted by SSA as income, even if she receives the maximum benefit rate.

Potential impact: SSDI

Per diem and reimbursement for actual travel-related costs are not considered income by SSA. However, the \$50 stipend would be considered income and be applied to the maximum monthly income Mattie is allowed to earn during the months that she receives the stipend. If she already receives the maximum substantial gainful activity amount, these earnings could affect her benefits.

Potential impact: housing and other means-tested programs

Mattie receives the \$50 stipend bimonthly (regularly), so the total amount (\$300) would count toward Mattie's annual household income. It is likely that the per diem and reimbursements would also be considered income. Both her eligibility and her rent may be affected by the income.

Example B

Jess participates in an organization's roundtable meeting. As compensation for her participation, she receives a stipend, meal cost reimbursement, and travel cost reimbursement.

Potential impact: SSI

The SSA does not count reimbursements as income. However, Jess's stipend would be considered earned income. Depending on the amount of the stipend, it may count as monthly income. If it is valued at less than \$65, the SSA will not count it as income. If it is for more than \$65, half of anything above that amount will count as income. If Jess makes the maximum federal benefit rate, the additional income will decrease her benefits dollar for dollar.

Potential impact: SSDI

The SSA does not count reimbursements as income. However, the SSA would consider Jess's stipend as income and apply it to the maximum income she is allowed to earn during the month that she receives the stipend. If she already receives the maximum substantial gainful activity amount, these earnings could affect her benefits.

Potential impact: housing and other means-tested programs

The gift card is not likely to count as income if it is a one-time payment. However, the reimbursements would probably be considered income. Her eligibility and/or her rent could be affected by the additional income.

Example C

Grant participates in a disability grant collaboration's focus group, for which he receives a \$20 gift card.

Potential impact: SSI

The gift card is in-kind earned income, but because it is less than \$65 it will not count as income, even if he makes the maximum federal benefit rate.

Potential impact: SSDI

The gift card would count as in-kind earned income and count toward the maximum monthly income Grant is allowed to earn during the months that he receives the stipend. If he already receives the maximum substantial gainful activity amount, these earnings could affect his benefits.

Potential impact: housing and other means-tested programs

The gift card would likely not count as income if it is a one-time payment.

Finding answers to your questions

The following agencies, specialists, and organizations can help you learn about the stipulations regarding your government benefits and determine whether compensation will affect the benefits you receive:

SSA claims representative – If you are a beneficiary of SSI or SSDI, there is a claims representative at the SSA's field office who is designated to help with questions. Contact your local SSA office for more information. If you have Internet access, you can find your local office

by going to the Social Security Office Locator on the website, Social Security Online, at perma.cc/497T-HXRY

- › Enter your postal ZIP Code to get the address, telephone number, and directions to your local office.

Protection and advocacy for beneficiaries of Social Security (PABSS)

– This program provides advocacy and other services to assist beneficiaries of Social Security secure or regain gainful employment. Every Protection and Advocacy agency has PABSS and could refer you to benefits counseling. To locate the program in your state, go to perma.cc/XX75-KZDA

National Association of Benefits and Work Incentives Specialists (NABWIS)

– Professional organization of the professionals who assist people who receive disability benefits. To learn more, go to perma.cc/8GC6-K3NP.

Listed below are some additional resources to help self-advocates get more information on work-incentives programs:

Work incentives planning and assistance (WIPA) – WIPA projects are community-based organizations that receive grants from SSA to provide all SSI disability beneficiaries (including

transition-to-work aged youth) with free access to work incentives planning and assistance. WIPA services are available in every state, the District of Columbia, and the U.S. territories. To locate the WIPA organization nearest you, call 1-866-968-7842 (Voice) or 1-866-833-2967 (TTY). You also can find contact information in the SSA service provider directory at perma.cc/29JW-7F98.

SSI work incentives – If you already receive SSI benefits and are thinking about returning to work, go to perma.cc/YCM8-FL8T for information about SSI work incentives.

For more information about work incentives for SSDI beneficiaries, go to perma.cc/244R-KHQH.

Additional resources

Disability.gov provides an online portal to some of the most frequently used websites related to disability benefits and resources, at perma.cc/634D-UULK.

The SSA website includes a number of links and resources about SSI and SSDI. The SSA's Red Book is an online resource for information about SSI, SSDI, and many work-incentives programs.

Housing Choice Voucher Program (Section 8) portal, at perma.cc/VS8K-FXFN.

Health Insurance Marketplace online fact sheet, at perma.cc/R3GQ-JWMS.

Compensation considerations checklist

Part A: General questions

Is a self-advocate providing service, expertise, or otherwise participating in a roundtable, meeting, focus group, or other event convened by your organization?

- Yes
- No

Does the self-advocate receive any of the following benefits?

- SSI
- SSDI
- Medicaid
- Section 8 housing voucher
- Section 811 supportive housing for persons with disabilities program housing
- SNAP; HUD housing programs other than those listed above; health insurance marketplace subsidies; low-income home energy assistance program
- No, the self-advocate does not receive any of these benefits.
- I do not know.

If the answer to the second question is “No,” there are no compensation considerations and you can compensate participants in whatever way you choose. If the answer to the second question is “I don’t know,” proceed to Part B.

If the answers to both of these questions is “Yes,” proceed to Part C, D, E, or F (depending on benefit type).

Part B: Does the person receive benefits?

To determine whether the self-advocate receives benefits:

- > Ask the self-advocate.
- > Ask the self-advocate’s guardian, if there is one.
- > Ask the self-advocate’s benefits coordinator if there is one (with the self-advocate’s permission).
- > Ask if the self-advocate has a representative payee who acts as the receiver of SSDI or SSI and, if yes, speak to that person (with the self-advocate’s permission).
- > Ask a direct service professional (with the self-advocate’s permission).
- > Use common sense — if you cannot find out, err on the side of caution and assume the self-advocate is receiving benefits.

If you discover that the self-advocate is receiving benefits, proceed to Part C, D, E, or F.

If you discover that the self-advocate is not receiving benefits, there are no compensation considerations and you can compensate in whatever way you choose.

Part C: Disability Benefits

If the self-advocate is receiving SSI:

Does the self-advocate receive the maximum federal benefit rate, \$750 for an individual or \$1,125 for a couple in 2018?

- Yes
- No

Does the self-advocate receive a lower amount?

- Yes
- No

If the self-advocate receives the maximum benefit, half of any additional income above \$65 of earned income, or \$20 of unearned income, will decrease the self-advocate's SSI or that month dollar for dollar.

If the self-advocate does not receive the maximum benefit, he or she can receive the difference between the maximum benefit and the actual benefit as additional income. The first \$65 of earned income and \$20 of unearned income still do not count as income.

Determine if your payment is income – Is it:

- expense reimbursement
- per diem
- earned income
- unearned income
- in-kind income (including gift cards)
- deemed income

If the payment is an expense reimbursement or per diem, it is not income. If the payment is any other type of payment, it is income.

If the payment is earned income:

- > The first \$65 per month is not counted as income. Half of everything over \$65 is income.
- > Does the additional income that is counted put the person's income above the maximum federal benefit amount? If not, the income will have no impact.

If the payment is unearned income:

- › The first \$20 per month is not counted as income. Everything more than \$20 is income.
- › Does the additional income that is counted put the person's income above the maximum federal benefit amount? If not, the income will have no impact.
- › If the payment puts the person's income above the maximum per month, whatever you pay the person will be deducted from the person's SSI.

If the self-advocate is receiving SSDI:

- › Is the person blind?
 - Yes
 - No
- › Does the person have any disability besides blindness?
 - Yes
 - No

Determine if your payment is income – Is it:

- expense reimbursement
- per diem
- earned income

- unearned income
- in-kind income (including gift cards)
- deemed income

If the payment is an expense reimbursement or per diem, it is not income. If the payment is any other type of payment, it is income.

If the person is blind, \$1,970 of income a month demonstrates substantial gainful activity and could affect benefits.

If the person has any other disability, \$1,180 of income a month demonstrates substantial gainful activity and could affect benefits.

If additional income will put the person above the allowable substantial gainful activity amount, the benefits are in jeopardy of being reduced or terminated.

If a person receives either SSI or SSDI, remember to inquire with the SSA or other agency about job programs and incentives.

Part D: Medicaid

If a person is on Medicaid:

Find out more about the requirements for Medicaid eligibility and relevant income limits in the person's state of residency at perma.cc/R245-NV9N.

Determine if your payment is income –
Is it:

- expense reimbursement
- per diem
- earned income
- unearned income
- in-kind income (including gift cards)
- deemed income

If the payment is an expense reimbursement or per diem, it is not income. If the payment is any other type of payment, it is income.

Check to determine if the additional income puts the person over the limit for Medicaid eligibility. The same exceptions for SSI apply to Medicaid income: The first \$20 of unearned income and the first \$65 of earned income are not considered income for this determination.

Part E: Housing

If the person receives housing assistance through Section 8, Section 811, or other public housing program:

Determine if the payment is income –
Is it:

- money received on a regular, reoccurring basis (monthly, weekly, etc.)

- a reoccurring disability payment
- a welfare assistance program payment
- another form of payment, monetary or not, which is not specifically NOT income

What is not income:

- > money received for, or in reimbursement of, the cost of medical expenses
- > temporary, nonrecurring, or sporadic income (including gifts)

If your payment is income, be attentive to the program's stipulations. All income is included in not only determining whether a person qualifies for a housing program, but in setting the person's rent. Even a slight increase in annual income could result in a rent increase.

Part F: Other benefits

Income can affect other benefits, including SNAP benefits, health insurance marketplace subsidies, and LIHEAP benefits.

Check with administrators of each program for eligibility information.

For more information

The Center on Victimization and Safety (CVS) at the Vera Institute of Justice works with communities around the country to fashion services that reach, appeal to, and benefit all victims. CVS's work focuses on communities of people who are at elevated risk of harm but often marginalized from victim services and the criminal justice system. We combine research, technical assistance, and the training to equip policymakers and practitioners with the information, skills, and resources needed to effectively

serve all victims. To learn more about CVS, contact cvs@vera.org.

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