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Making Ends Meet: How Low-Income DI Beneficiaries Meet Their Needs

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ABSTRACT

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Making Ends Meet: How Low-Income DI Beneficiaries Meet Their Needs

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Key findings and implications

More than one in three Social Security Disability Insurance (DI) beneficiaries are living in- or near-poverty and how these low-income beneficiaries make ends meet is uncertain. One possible explanation is that DI beneficiaries' primarily base their consumption on their income and therefore their consumption levels are low. A second possible explanation is that DI beneficiaries have access to resources to support consumption at levels beyond what is suggested by their poverty level income, for example in-kind income or informal income.

This study assessed how low-income DI beneficiaries make ends meet. We used qualitative methods, interviewing 35 low-income DI beneficiaries living in the Worcester Massachusetts area to determine how they managed their income, expenses, savings and debt to meet their needs. The interviews with study participants included questions on expenses, income, savings, debt, strategies to make ends meet, and wellbeing. We use participant's reported expenditures and in-kind income to obtain an estimate of total consumption. The study participants were not randomly selected and the findings cannot be generalized to the national population of low-income DI beneficiaries.

We found that

- Study participants used their formal income, mainly DI payments, to support most of their consumption and thus, consumption levels for most were low. Nearly all participants reported living month-to-month without accumulating savings or debt. Most participants reported that they were 'just getting by' or 'finding it difficult to get by.'
- In addition to formal income, study participants used in-kind resources and informal income to support consumption. With the exceptions of health care, these resources were relatively modest. Nearly all participants accessed healthcare services through Medicare and Medicaid with minimal out-of-pocket expenditures. Public housing subsidies accounted for approximately 34% of participants' housing consumption and SNAP food assistance accounted for approximately 27% of participants' food consumption.

- Nearly all participants reported consumption limitations and some participants reported more severe hardships including homelessness, skipping meals, or having very limited food quantity or quality at the end of the month.

The policy implications of the findings are:

- Policies and programs to support higher levels of consumption would improve low-income DI beneficiaries' material wellbeing and alleviate hardship. These include: (a) DI employment incentives and supports that focus on employment at levels below substantial gainful activity, (b) increased DI benefit amounts for beneficiaries with low benefit amounts, and (c) more favorable treatment of persons with disabilities in eligibility determinations and benefit calculations for means tested assistance programs.

- Policies and programs to decrease homelessness and increase housing stability would lessen hardship. These include: (a) emergency assistant payments to DI beneficiaries that are at risk of homelessness, (b) refundable housing tax credits for low-income DI beneficiaries living in areas with high housing costs, (c) targeting of homeless DI beneficiaries for programs that provide rental assistance, case management services and clinical services to hasten the transition from homelessness to stable housing.

I. INTRODUCTION

Approximately 38% of DI beneficiaries are living in- or near-poverty with income of less than 150% of the Federal Poverty Level (FPL) (Bailey and Hemmeter, 2015).[1] The goal of the qualitative study reported here is to determine how low-income DI beneficiaries make ends meet. In other words, how do they manage their budget components including income, expenses, savings and debt?

There is a lack of detailed information on how low-income DI beneficiaries make ends meet; however, there is detailed qualitative research on how low-income single mothers receiving welfare assistance in the 1990s made ends meet (Edin & Lein, 1997). Edin and Lein found that the welfare cash payments contributed to meeting families' basic needs; however, the cash payment alone generally covered less than one-half of the families' essential monthly expenses. Low-income single mothers made ends meet by combining a variety of cash income sources and in-kind assistance. In the order of their relative contribution, these were the following: public in-kind assistance (e.g. Food Stamps), cash assistance from family or friends, work, and non-welfare community agency assistance. In addition to augmenting their welfare payments with other income and in-kind assistance, some families were able to reduce the costs of essential needs, for example reducing rent by doubling up and living with family and friends. Edin and Lein did not estimate the value of these in-kind contributions. These findings indicate that welfare payments account for less than half of the resources these families use to make ends meet. The low-income mothers were able to use non-welfare income and in-kind assistance from public programs and from families and friends to achieve consumption levels that exceeded what would have been possible with welfare income alone.

How do low-income DI beneficiaries make ends meet? One possible explanation is that DI beneficiaries primarily base their consumption on income. This suggests that beneficiaries have very limited levels of consumption. The poverty- level income for a one-person household in 2018 is $1,012 per month. To put poverty-level income into the context of living expenses, the 40th percentile fair market rent in Worcester, Massachusetts, the area in which this study took place, is $850 per month for an efficiency apartment (US Department of Housing and Urban Development, 2018). The United States Department of Agriculture (2018) estimated cost of a 'low-cost' food plan for food prepared at home for a one-person household is $240 per month. Thus, the costs of just two basic needs, food and shelter, exceed the poverty level income by $78 without covering the costs other common expenses including transportation, healthcare, clothing or personal care. Is it possible for beneficiaries to make ends meet on poverty-level income given the costs of basic needs?

A second possible explanation is that DI beneficiaries have access to resources to support consumption at levels beyond their poverty level income. Income as a percentage of poverty is an imperfect measure of wellbeing and some resources available to households are not counted in the income used to determine a household's poverty level (Meyer & Sullivan, 2003). For example, low-income households may receive Supplemental Nutrition Assistance Program SNAP benefits to purchase food or housing subsidies to cover a portion of their housing costs.

[1] Approximately 52% of beneficiaries have income of less than 200% FPL.

These in-kind income sources are not counted in the determination of a household's poverty level. In addition, some low-income households may have informal income that is not reported and also not included in the poverty level determination. Informal income could include cash assistance from family or friends or income from unreported employment.

Prior analyses of survey data indicate that some low-income DI beneficiaries have in-kind income from public programs. Using data from the Survey of Income Program and Participation, Bailey and Hemmeter (2015) estimate that 4.2% of DI beneficiaries receive energy assistance, 13.0% receive housing subsidies, and 33.8% receive SNAP benefits. These percentages were estimated across all disabled-worker beneficiaries and we expect that the percentages are somewhat higher among low-income DI beneficiaries. Using the National Beneficiary Survey, Livermore and Bardos (2014) estimate that 90% of beneficiaries living in households with income of less than 100% FPL are Medicare beneficiaries and 50% are Medicaid recipients.

The extent to which low-income DI beneficiaries receive informal in-kind or cash assistance is unknown. For example, a beneficiary may be living as a single-person household in the home of parents or friends and through this arrangement receive in-kind housing, food, and transportation assistance. Comparably, family, friends or partners may provide informal cash assistance. If these additional resources are considerable, it is possible that low-income DI beneficiaries have higher levels of consumption than is suggested by their income. We are not aware of any studies that estimate receipt of informal income among low-income DI beneficiaries. Cook and colleagues (2004) examined the personal economies of approximately 1,500 people with severe mental illness living in the community and found that some study participants had informal income. An estimated 15% received cash assistance from family or friends and 10% received income from odd jobs or illegal activities that was not reported

A third potential explanation for how low-income DI beneficiaries manage their financial resources is that they use savings or incur debt to pay for current consumption. We are not aware of any prior studies that estimate this.

In this qualitative study, we interviewed 35 low-income DI beneficiaries to determine how they made ends meet. These interviews included questions on expenses, income, savings, debt, strategies to make ends meet, and wellbeing. We also asked questions about public and informal in-kind income and informal cash income to estimate participants' income. We use participant's reported expenditures and in-kind income to obtain a rough estimate of total consumption. To provide additional context to how study participants made ends meet, we also collected and analyzed data on participants' demographic characteristics, DI participation, employment history, paths to DI, disability, health status, wellbeing and future expectations for employment and DI participation.

II. METHODS

A. Study participants

We conducted interviews with 35 DI beneficiaries living in the greater Worcester area in Massachusetts. The project was reviewed and approved by the University of Massachusetts Medical School Institutional Review Board (IRB).

Worcester is the second largest city in New England with a population of approximately 184,000. Approximately 16% of the population is Black or African American and 21% is Hispanic or Latino. The poverty level for adults age 18 to 64 is 21%. The estimated percentage of persons with disabilities aged 18 to 64 is 13%.[2] The Worcester area unemployment rate at the time of the study ranged from 3.7% to 4.7%.[3]

Participants were recruited through a variety of methods to ensure a heterogeneous sample. This includes recruitment through disability serving agencies and community-based organizations (CBOs). These CBOs included state vocational rehabilitation offices, Career Centers, Independent Living Centers, peer-operated recovery programs, community mental health and social service programs. In addition, we recruited participants through programs managed by UMass Medical School's *Work Without Limits*[4] initiative, including a Social Security Administration-funded Work Incentive Planning and Assistance (benefits counseling) program and an Employment Network (Ticket-to-Work program).

We also recruited participants through social media strategies, including a Craigslist advertisement and through *Work Without Limits* website and Facebook page. Finally, we used a snowball sampling method and asked individuals who volunteer for the study to share information about the study with others who might be interested in participating.

Recruitment materials instructed potential study participants to contact the researchers to volunteer for the study. Potential participants were screened for eligibility by phone and were included when they met the following criteria: (a) currently receives DI benefits based on own work history, (b) concurrently receives SSI or SNAP (an indication of low income status) or receives an DI payment of less than $1500 per month[5], (c) is between ages 24 to 67, (d) is community dwelling, living in the greater Worcester area, (e) speaks English or uses American Sign Language, and (f) not under guardianship of another or otherwise unable to provide own consent.

[2] These statistics are estimates from the U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates.

[3] The unemployment rate was for the December 2017 to April 2018 period. The estimates are from the U.S Department of Labor, Bureau of Labor Statistics.

[4] *Work Without Limits* is a disability employment initiative managed by the UMMS Center for Health Policy and Research's Disability, Health and Employment Policy Unit.

[5] In Massachusetts, the SNAP gross income eligibility limit for persons with disabilities is 200% FPL. People that do not qualify for a SNAP benefit based on net income qualify for a $17 minimum benefit..

B. Interviews

Each participant was interviewed either two or three times by experienced qualitative interviewers. At the start of each interview, study participants were informed in writing of the purpose of the study, that their participation was voluntary, that information provided would be confidential and that the sessions would be audio-recorded. Prior to the first interview, participants were asked to complete a brief questionnaire to collect demographic and disability information.

Three semi-structured interview guides with open-ended questions were used to guide the interview discussions. In all interviews, we used non-assumptive probes and follow-up questions to encourage participants to elaborate and provide examples from their own experiences. Each interview lasted approximately 1 hour; interviews were audio-recorded and participants received $150 for participation in the study ($50 for each of the three interviews). The interviews were conducted between November 2017 and April 2018.

Each interview had a different focus. The first interview focused on participants' living situation; disability, health and disability benefits; and education and employment. The second interview focused on participants' expenses, income, savings, debt, strategies to make ends meet, and wellbeing. In addition to the interview guide, a budget worksheet was used during the second interview. The budget worksheet was an itemized list categorized by expenses, income, assets, loans and debt. The objective was to collect approximate budgets focusing on major items. It was not our objective to obtain a detailed accounting of every item in participants' budgets. During the second interview, participants were first asked about expenses prior to being asked about income because people may be more willing to talk about expenses compared to income. If the reported expenses and income did not balance, we asked additional follow-up questions to attempt to reconcile the discrepancy. The third interview included questions on employment, employment supports, and work incentives.

All 35 study participants completed the three interviews. The majority of participants (26) were interviewed at their residence. For participants that were homeless, residences included shelters, temporary housing for the homeless, and motels. Three participants were interviewed at our University of Massachusetts Medical School offices, four participants were interviewed at community-based organizations and two participants were interviewed at other community locations.

C Data and analysis

There were three sources of data used for the analysis: the participant questionnaire, the budget worksheet, and the qualitative interviews. All data were self-reported by the study participant. Descriptive statistics were generated from the participant responses to the questionnaire to summarize the participant characteristics, including age, gender, education, and disability.

Descriptive statistics were also generated from the budget worksheet to summarize participants' cash income, expenditures and consumption. All budget amounts and summary statistics were reported as monthly amounts and were based on the participant's circumstances in the month of the interview. We included SNAP benefits as part of cash income because SNAP

may be used in ways that are comparable to cash for purchasing unprepared food. We counted purchases using SNAP as expenditures. The budgets were generated for one-person households. Except for one participant living as part of a married couple, participants living with others were either living as roommates sharing housing expenses while paying other expenses separately or living as a boarder in their parents' home.[6]

Expenditures were grouped into the following categories: housing, food, transportation, phone, health care and 'other expenditures.' Housing expenditures included rent or mortgage and utilities. For people who were homeless and incurring no housing costs, for example people living in shelters or temporary housing for the homeless, we estimate their housing expenditures to be $0. For people that were homeless and incurring housing costs, for example motel payments or day-to-day payments to friends/acquaintances, the costs were highly variable from week to week. We approximated the housing expenditures at the time of the interviews; however, because of the short-term variation, the long-term accuracy of the estimates is uncertain. Food expenditures included costs for food at home and food away from home and included food purchased with SNAP benefits. Transportation expenditures included car expenditures (loan/lease payments, gas/repair, and insurance), public transportation, and payments for rides (taxis, Uber, and informal payments). For the most part, phone expenditures were for participants' phone plans; however, in some cases it was difficult to separate the costs of the participants' phone services from other costs. For some, the phone costs also included internet costs or costs for other people, for example boyfriend/girlfriend or children. Thus, the estimated phone expenditures likely overestimate the actual phone expenditures. Health care expenditures included premiums, co-payments, deductibles and other out-of-pocket health care expenditures. The remaining expenditures that participants reported were considered "other" expenditures. These varied considerably in type and amount across participants and included credit card interest; loans or debt payments other than car loans; storage; clothes; tobacco products; alcohol and other substances; personal care or household items; cable/internet; and gym memberships.

To account for in-kind income in the form of housing subsidies we estimated the in-kind income amount as the difference between the participant's rent and the HUD fair market rent (40^{th} percentile) for the housing (See Results Section for additional detail). As a rough approximation, we assumed that participant's in-kind income for food, transportation and other to be 10% of their actual expenditures. The basis of this assumption is described in the Results Section.

Interview audio recordings were transcribed verbatim by a professional transcriptionist; transcripts were checked by the researchers for accuracy. The transcripts were coded using ATLAS.ti (version 8). As interview transcripts became available, we undertook a line-by-line open coding of the transcripts to identify emerging themes. Coded themes from the first interviews were grouped into provisional conceptual categories. The categories were chosen to be consistent with the research objectives of describing how low-income beneficiaries make ends meet. As subsequent interview were coded, themes were examined to determine if they were

[6] To determine the one-person budgets for the member of the married couple, the couple's expenses were divided by two and one-half of the non-participant spouse's income in excess of the spouse's income was considered cash 'family income' of the participant.

consistent with existing categories or represented new categories. We used this iterative, constant-comparative approach (Corbin & Strauss, 2008) to code all transcripts, creating a final set of conceptual categories and selecting quotes representative of common themes and concepts across study participants.

The data in this study is presented in a manner to protect participants' identities. For example, we redact locations and names from quotes and we do not identify the gender of study participants. When presenting non-aggregated data, for example a scatterplot, random offsets were added to each data point. Participant quotes are not verbatim; we made minor edits for grammar and clarity.

III. RESULTS

The results were based on interviews with 35 low-income DI beneficiaries. We group results into different sections including participant characteristics, overall financial status, income, expenditures, consumption, monthly budgeting, and future plans.

A. Participant characteristics

Table 1 provides study participant characteristics. The statistics were estimated using data from the demographic questionnaire and the participant interviews. Eighteen participants were 50 years of age or older and only 3 participants were under age 30. There was a range of education levels with 11 participants having completed a 4-year college or postgraduate degree and 12 participants having a high school education or less. Three participants were Hispanic and 6 participants were Black or African American. Approximately one-third of participants (13) were female. Twenty participants reported that they were single and had never been married; only two participants reported currently being married or part of an unmarried couple. Nineteen participants were living alone. Except for 2 participants that were in the Medicare waiting period, all participants were Medicare beneficiaries. Nearly all participants (34) also participated in the Massachusetts Medicaid program, MassHealth

Table 1: Study Participant's Characteristics

Characteristic		n	Percent
Age	29 or less	3	8.6
	30 to 39	5	14.3
	40 to 49	9	25.7
	50 to 59	13	37.1
	60 or older	5	14.3
Education	High School or Less	12	34.3
	Some college or vocational education	12	34.3
	Completed 4-year college degree	10	28.6
	Postgraduate degree	1	2.9
Hispanic		3	8.6
Race	Black or African American	6	17.6
	White	26	76.5
	Other race	2	5.9
Female		13	37.1
Marital Status	Married or member of an unmarried couple	2	5.7
	Divorced, separated, or widowed	13	37.2
	Single, never married	20	57.1
Living Alone		19	54.3
Housing Status	Public Subsidy	14	40.8
	Family Subsidy	3	8.6
	Market Rate Apartment, living with others	8	22.9
	Market Rate Apartment, living alone	2	5.7
	Homeless	8	22.9
Insurance			
	Medicare and Medicaid	32	91.4
	Medicaid only	2	5.7
	Medicare only	1	2.9

The study population was younger than the national population of low-income beneficiaries; 26% of the study population was under age 40 compared to 14% of the national population. Sixty-six percent of the study population had education levels exceeding high school and this was higher than national population, 50%. The percent Hispanic were comparable, 9% for the study participants and 12% for the national population. The percent Black or African American were also comparable, 18% for the study participants and 24% for the national population. The national population had a higher percentage of females, 49%, compared to the study participants, 37%. The study population also had a higher percentage of single, never married participants, 57% vs. 34%.

We compare rates of program participation to those documented in Livermore and Bardos (2014). Using the National Beneficiary Survey, they estimated that 90% of beneficiaries living in households with income of less than 100% FPL were Medicare beneficiaries and 50% were Medicaid recipients. Among study participants, 94% were Medicare beneficiaries and 97% were Medicaid recipients.

We are not aware of estimates of living arrangements for the national population of low-income DI beneficiaries. Bailey and Hemmeter (2015) estimated living arrangements for all DI disabled worker beneficiaries. Compared to all disabled worker beneficiaries, a greater percentage of the study participants lived alone, 54% vs. 23%.

We use Bailey and Hemmeter's (2015) SIPP-based estimates of the demographic characteristics of the national population of all DI disabled worker beneficiaries with family income of less than 150% FPL as a comparison to the characteristics of the study participants.

B. Disability and health

Based on data from the participant questionnaire, 31 participants reported that they were limited because of physical, mental or emotional problems; 12 participants reported special equipment; 22 had trouble learning, remembering or concentrating; 8 reported limitations in activities of daily living, and 13 had limitations in instrumental activities of daily living.

Using data from the participant interviews, 26 participants reported having a mental illness; reported conditions included bipolar disorder, depression, anxiety disorder, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), attention deficit hyperactivity disorder (ADHD), schizophrenia, psychotic disorders, schizoaffective disorder, and agoraphobia. We did not collect data on the severity of the psychiatric conditions. We also did not specifically ask about prior hospitalizations; however, approximately one-half of participants that reported a mental illness also reported prior psychiatric hospitalizations.

The following are a sample of participant descriptions of their mental health conditions:

I have schizoaffective disorder and depression disorder. When I'm not my meds and I'm not up to my best, I would hear voices, see things, and be very depressed about it.

I have been diagnosed with severe bipolar, ADHD, OCD, anxiety and depression. I was raised in the system since I was six -- residential programs and alternative schools for students with attention disorders and learning disabilities.

Sixteen participants reported physical disabilities. Self-reported conditions included: paralysis, neuropathy, arthritis, spondylosis, back pain, joint pain, pinched nerve, hearing loss, heart disease, celiac disease and chronic pain. Three participants received personal assistant services (PAS) services through Medicaid.

The following are a sample of participant descriptions of their physical conditions or disabilities:

I had my titanium rods put in my neck and I had my lower back fused as well, so they're both fused. And I had three bulging discs. I've got neuropathy, spondylosis, and degenerative joint disease. I have neuropathy and osteoporosis. I have celiac disease and arthritis.

I was involved in a car accident, after that, I was expected to be a quadriplegic

I have 80 percent loss of function on my left leg and the other one is about 60 loss. I have shooting pains in my toes and so I have like sciatic and back issues and balance and safety issues. I have a personal care attendant that comes in six days a week

Four participants reported cognitive or developmental disabilities.

I had a head injury as a baby. I was in a car accident.

I was in an accident and now I have trouble concentrating and remembering.

Participants were asked to describe their physical health status. Approximately three-quarters of participants' descriptions indicated their physical health was fair or better, for example,

My physical health is probably not as good as it should be, but it is fine.

My physical health is fair. I'm overweight. I really haven't been successful trying to lose weight, but I am trying to tweak my diet here and there. I'm really trying to cut down on carbs.

The remaining one-quarter of participants' descriptions indicated their physical health was poor or very poor.

My physical health is very poor; my foot, my spine, my lower back and shoulder. I have joint pain.

It is poor. I have really bad lungs. They're in bad shape. I am always in pain. I take ibuprofen over the counter, and aspirins, but I start bruising when I do the aspirins.

I am in pain all of time.

Participants were also asked about their mental health status. Among participants that reported a mental health condition, approximately 80% of participants' descriptions indicated that their mental health was fair or better, for example,

Once in a while the panic comes on and I'm on Klonopin for that. And I'm on Paxil. My mental health is okay now although I worry a lot.

More stable right now. Sometimes I am in a bad mood, but I control it because I'm taking the medication, I see my therapist. I try not to be depressed. I try not to be thinking about suicide.

Well, it's gotten better. I think it's gotten better. It goes up and down. I've always had thoughts of suicide. I have thoughts of just hopelessness and confusion, not knowing where I'm really supposed to go from here. It's kind of like that every day. I just have to keep myself in check and just keep moving or keep doing something.

Approximately 20% of participants' descriptions indicated that their mental health status was poor or worse. For example,

My mental health is poor, working on getting to fair. A big problem for me throughout the years has just been that I've never really been able to predict my energy level or functionality. And now, it's getting a little bit better because of my improved treatment from my new doctor. For more than 15 years it was consistently bad, with just the occasional random benefit of feeling like the clouds are parting a little bit, or I was able to defog a little bit.

Poor. I have a lot of self-defeating thinking -- self-defeating concepts and negative thinking. I've learned enough not to act on it. The self-defeating thoughts are detrimental to my sobriety and my mental and physical health. If I stay on medication, I do better.

I have been diagnosed with bipolar and depression and have had problems since I was 12. I have PTSD. After I had my second son, I had postpartum depression. I have been in and out of institutions for the last 14 years.

I'm just kind of freaked out because I hear a lot of voices; sometimes they cave in my head and embarrass me. People told me telepathy doesn't exist and they put me on tons of meds.

C. Employment history

Participants reported a variety of occupations, the majority of which were low-wage. Most participants' work history included jobs in more than one occupation. Based on self-reported occupations, participants' occupational groups and occupations[7], included the following: office and administrative support (administrative assistant, receptionist, desktop publishing, data entry clerk, stockroom worker, grocery store stocker); construction (laborer, painter, roofer, carpenter); maintenance (auto repair technician), production (printing worker, woodworker); transportation (delivery driver, bus driver, cab driver), healthcare practitioners (nurse, certified nursing assistant, home health aide); computer (software support worker); food preparation and serving (fast food and counter worker, cook, dishwasher, food preparation worker); education (teacher, teacher's aide, tutor); community and social service (human service worker); arts, entertainment and sports (musician, photographer, athletic coach, theater set designer); building, grounds, and

[7] The occupational groups and titles are from the Bureau of Labor Statistics: https://www.bls.gov/oes/current/oes_nat.htm

cleaning (landscaping, janitor, housekeeper, maintenance worker), personal care and service occupations (animal care worker, personal care assistant); protective service (security guard); sales (retail sales worker, cashier, sales representative); and engineering (engineering technician).

Participants described their occupational history:

I've been in construction most of my life. – house building, roofing, digging ditches, and building fences.

I had a lot of warehouse jobs, unloading trucks then working in the backroom.

I was a CNA for a nursing home for seven years and then a home health aide.

I was a housekeeper at [hotel]. Afterward I tried out room service. I worked at stores – you name it. I worked at a lawyer's office eventually.

We did not collect data on study participants' wage histories; however, participants' descriptions of their jobs suggest most were low-wage. As an exception, four participants reported at least one middle- or high-wage job.

As a matter of fact, the last job I worked… in [redacted year] was at $95K. I started the job at $85K and then I got a $5,000 bonus and a raise and the next year I got another one so that put me at $95K.

I just wanted to get a job. I got a job at [business organization] as a temp and that really didn't work out. And I bounced around with temp positions for a few years. I did get a job at a telecommunications company and after three months I was given a full-time position, $35,000 a year. This was more than money I'd ever seen in my lifetime, but unfortunately the economy started really going south and they had to let people go.

One year, the best year I ever had, I was working at [corporation]. I worked there for six months. I made about $15,000. That was a $30,000 a year job.

I landed the job for $35,000 a year, full benefits. I thought, I don't need this welfare [DI], I'm going to get off it. I did that for a year and a half. Then the recession happened and five of us were laid off.

Nearly all participants had jobs after the onset of their disability and attempted to be self-supporting through employment after disability onset. For some, this period spanned many years and many jobs. During attempts to be self-supporting, all participants were able to secure employment; however, most were not able to secure stable, long-term employment. Participants described periods of job instability related to poor health, employer layoffs, or terminations.

I was working at [corporation] for almost two years. I had such bad anxiety that I was missing time and was fired.

Well, I started off in the mail room, and then I got like a production assistant job. But money was always very tight. The owner did not pay his employees well. And the day the company closed, he faxed over a notification to the workers who were still there in the plant.

I was in the fitness industry for about a good two years. I managed to do very well for a little while but I decided to take myself off the medications thinking I could manage without them which was not the best choice. I lost my license, my vehicle and my reputation.

I was bouncing from job to job for years. I couldn't maintain a job. There would be some jobs that I would do okay and there would be some jobs I wouldn't. I have always had a lot of chronic back pain, so my back would go out for no reason at all. The longest job I've held through my work history was four years.

I worked in printing making pretty good money. I worked for a solid two years and the factory would up closing down without notice.

Three to four years ago I was working at [store]. I was doing well but it was hard for me to focus. They noticed that I wasn't working as well and I ended up in the hospital.

Participants reported that job instability also resulted in financial instability.

After I got out of college and tried working. I did it for ten years. I was getting jobs here and there. But I couldn't hold a job. And I had no money coming. I was poor. I was living at my parents' house. I had no money. It was awful.

It just came to the point where I was having a really hard time maintaining work and I couldn't find something stable long enough to maintain a normal living situation, to meet my basic needs, to have a roof over my head.

I worked for a while; but, I was never able to rise above poverty level despite the fact that I'm very well-educated. I went from one bad job to another bad job. And then I had a problem in my family, my mother died, and I became homeless. I had problems with depression all my life and it got so bad at that time. I saw a doctor and she told me, "You're very, very depressed, in case you don't know it." And she said, "You have to go on disability if you want to be able to survive."

D. DI participation

All study participants were DI beneficiaries and 3 participants were also SSI recipients. In addition, there we three DI-only study participants that formerly received adult SSI. The age and duration of disability benefits described below were based on the first receipt of DI or SSI, whichever was earlier. Twenty-five participants started receiving DI/SSI before age 40; only 3 participants started receiving DI/SSI at age 50 or older (See Table 2). At the time of the interview, 6 participants had been receiving DI/SSI for 5 or fewer years and 10 participants had been receiving DI/SSI for 20 years or more.

DI monthly payments among participants were generally low with more than two-thirds having payments of less than $1,000 per month. DI monthly payments also provide information

that we can use to estimate beneficiaries' earnings histories.[8] These estimates indicate that study participants' average earnings prior to DI were low. Average indexed monthly earnings were less $900 for 12 participants; 11 participants were between $900 and $1299 and 12 participants were $1300 or greater.

Table 2. DI Participation Characteristics among Study Participants

Characteristic	n	Percent
Age at First DI Award or First SSI eligibility		
29 or less	12	34.3
30 to 39	13	37.1
40 to 49	7	20
50 to 59	3	8.6
Total Years Receiving DI and/or SSI		
5 or fewer years	6	17.1
5 to 9 years	10	28.6
10 to 14 years	4	11.4
15 to 19 years	1	14.3
20 years or more	10	28.6
DI Monthly Amount		
$475 to $749	6	17.1
$750 to $999	18	51.4
$1000 to $1249	6	17.1
$1250 to $1500	5	14.3
Average Indexed Monthly Earnings (2018 dollars)		
$500 to $899	12	34.3
$900 to $1299	11	31.4
$1300 to $1999	6	17.1
$2000 to $3100	6	17.1

E. Paths to DI

Each study participant's path to DI was unique; however, there were similarities among subgroups of study participants and we used these similarities to define four primary paths.[9] The first path, *SSI Path*, was characterized by participants' receipt of SSI prior to DI. Five study participants followed this path. Four of these participants reported having disabilities prior to age 18 and became adult SSI recipients between the ages of 18 and 22. The fifth of these participants reported an onset of a mental illness in his/her thirties and became an SSI recipient at that time. Among the four participants with disabilities prior to age 18, two reported cognitive impairments due to injuries and two reported psychiatric disabilities. Subsequent to the start of SSI, all 5 participants worked at levels sufficient to become DI beneficiaries. Four of these transitioned from SSI to DI-only, and one participant continued to receive both DI and SSI. Of

[8] DI payment amounts are based on beneficiaries' earnings history as measured by the Average Indexed Month Earnings (AIME). The AIME is based on DI beneficiaries' average annual earnings since age 22 with the exclusion of certain low earning years. In 2018 dollars, DI beneficiaries' payment amount (Primary Insurance Amount, PIA) was calculated as 90% of the worker's AIME up-to $856 plus 32% of the AIME between $856 and $5157 plus 15% of the remainder. We used study participants' reported DI amount to calculate their AIME as an approximate measure of their average monthly earning amount prior to DI. https://www.ssa.gov/oact/cola/piaformula.html

[9] We define mutually exclusive paths; however, there is some minor overlap where participants fit the characteristics of more than one path. Two participants did not fit the characteristics of the four paths.

the five participants, two have maintained consistent part-time employment for more than 10 years and the other three were no longer working.

> *The social worker in the hospital suggested I get on SSI and I did, about $400 a month. And then I went to college and got a degree. I figured after college I could work. I had a degree. Well, it wasn't as easy as I thought it would be. I had a lot of cognitive disabilities that I didn't understand at the time. I tried working for ten years, working on and off and I finally applied for DI.*

The second path, *Young Adult Injury,* was characterized by participants' onset of disability in their twenties because of an injury and included 3 participants. These participants had physical disabilities (paralysis) and/or cognitive disabilities. Two of these participants were in college at the time of the injury and applied for DI while hospitalized for their injuries. They were awarded benefits soon after application. The first of these was injured approximately 5 years ago and has since returned to part-time employment and plans to return to college. A second of these, injured approximately 20 years ago, completed college, obtained professional employment and exited DI for short period of time. This participant has subsequently returned to DI and is no longer employed. The third participant, injured approximately 5 years ago, returned to full-time employment following the injury; however, because of physical and cognitive disabilities subsequently stopped working and applied to DI. Subsequent to the DI award, this participant resumed employment and is currently working part-time.

> *I got hurt in [redacted] and I was in a coma for a month. And while I was still asleep in the coma, my family applied for Social Security. I was in the hospital and the rehab center for another five months. I got out of the hospital. Within two or three months, my Social Security was processed and approved and I received the back payments.*

The third path, *Work Instability and Mental Illness,* was characterized by participants' reported childhood or early adult onset of a mental illness and history of work instability after the onset of mental illness. Work instability included frequent transitions from job to job because of layoffs, terminations for cause, and job quits. Among the 17 participants following this path, the period of work instability ranged from years to decades. We do not have the data to determine the reasons for the job instability; however, several participants reported that job instability was related, at least in part, to poor mental health. It is also possible that labor market conditions, for example layoffs or the instability of low-wage employment, contributed to work instability.

> *I kept having mental breakdowns at work, some kind of psychosis. I just kept on breaking down. I couldn't hold a job. Major depression and stuff like that. So I ended up being hospitalized.*

> *I have anxiety and bipolar. That was my diagnosis. I could always get a job and was always working. The thing is, I was switching jobs every other month. It was just because I couldn't pay attention. I was getting fired. It wasn't something bad that I did, it was just the fact that I couldn't remember things.*

The fourth path, *Older Adult Onset* was characterized by participants' disability onset at older ages, in their forties or fifties. There were 8 study participants that followed this path and they reported limitations because of chronic back pain, joint problems, heart disease, diabetes or mental illness.

Then I had surgery again. And then after that surgery I had to go to rehabilitation. My landlady evicted me while I was recuperating from surgery. I applied in [year] when things were crashing down around me. I really needed to apply. I know people don't always get it on the first try but I really needed the money to pay my bills.

I had a severe nervous breakdown in [year] while working as a [occupation] and was hospitalized for several months during that year. I had very persistent depression and it was decided that I could apply and I received it on the -- I guess they call it the first round. As time has gone on, other aspects of my physical health have declined.

F. DI application experiences

Participants were asked to describe their experiences when applying for DI. Experiences varied; however, we found two common experiences among subgroups. Approximately one-third of study participants reported that their application was related to a physical or psychiatric hospitalization. In most cases, participants reported that applications were approved without appeal. In most of these cases, the applications were facilitated by health care provider or social service agency staff.

I was suicidal. I was hospitalized for about 30 days. I applied while I was in the hospital. When I got out, I had an interview with Social Security within a few months and then I was approved.

I had a lot of bipolar and PTSD things happening. I was hospitalized and while there a social worker suggested that I apply. I applied and was approved.

Approximately one-fifth of study participants reported that their application was initially denied and subsequently approved after lengthy appeals processes.

The process was long and tedious and riddled with file, denial, and repeat. File for consideration or appeal. Denied. File again for this one review, next review, and then it ended up with an administrative law judge.

It took me a long time. I think it was almost six years. I was denied, I appealed, I went through so much, until I almost lost my mind. I really had to fight to keep my mind. I went through many, psychological doctors. It was just awful. It was awful.

G. Overall financial situation

Participants were asked "Overall, which one of the following best describes how well you are managing financially these days?" Most participants reported that they were either 'just getting by' (15) or 'finding it difficult to get by' (11); only 5 participants reported that they were 'doing ok' and 2 participants reported that they were 'living comfortably'. Participants described the basis of their overall financial assessment. A consistently employed participant with a housing subsidy indicated that he/she was living comfortably:

My rent is subsidized. Plus, I work 20 hours a week which is pretty good. I bring home more than one hundred and something dollars a week and I get few dollars for food stamps. So it's okay.

A participant living in public housing reported that he/she was 'just getting by' and he/she described his/her circumstances:

> *My situation is challenging. I just sometimes don't have enough coming in to make what's going out. I'm comfortable on a day to day basis. With no ability to save, I'm very weary.*

A participant who was homeless and staying at a shelter indicated that he/she was 'finding it difficult' and described his/her financial situation as follows:

> *"Well it is difficult, it can be very difficult. I'm stringing it, managing it, and just barely staying above water. I've been treading that water for a long time.*

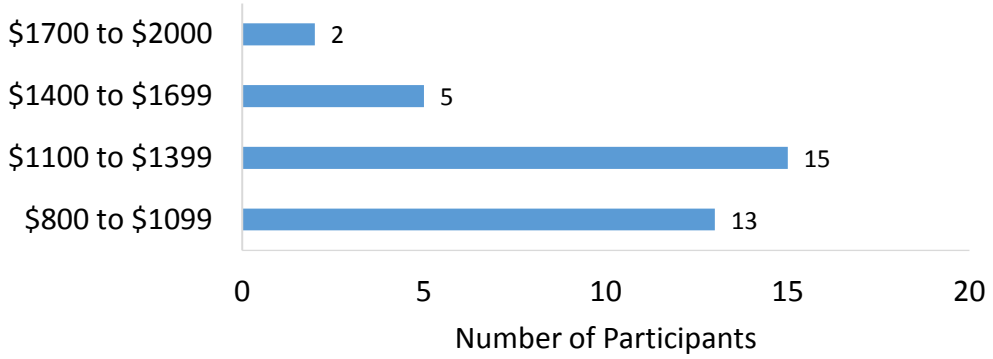
A few participants indicated that their overall financial situation was worse than 'finding it difficult.' One participant reported a 'dire' financial situation:

> *I'm desperate. My financial situation is dire. I have to resort to doing things that are bad for me to pay my expenses. I hope the picture that I am giving shows that, without the help I get, I would be homeless.*

H. Participant total cash income

Participants reported their income sources and amounts. Cash income included the following: DI payments, SSI payments, SNAP benefits, reported and unreported earned income, cash assistance from family, friends, and cash assistance from means tested programs. We include SNAP benefits as part of cash income because SNAP may be used in ways that are comparable to cash for purchasing unprepared food. Among study participants, the average cash income was $1218 (SD $273). The total cash income of study participants was low with 28 participants reporting less than $1400 per month. The distribution of total cash and SNAP income is shown in Figure 1.

Figure 1. Distribution of Participants' Total Cash and SNAP Income

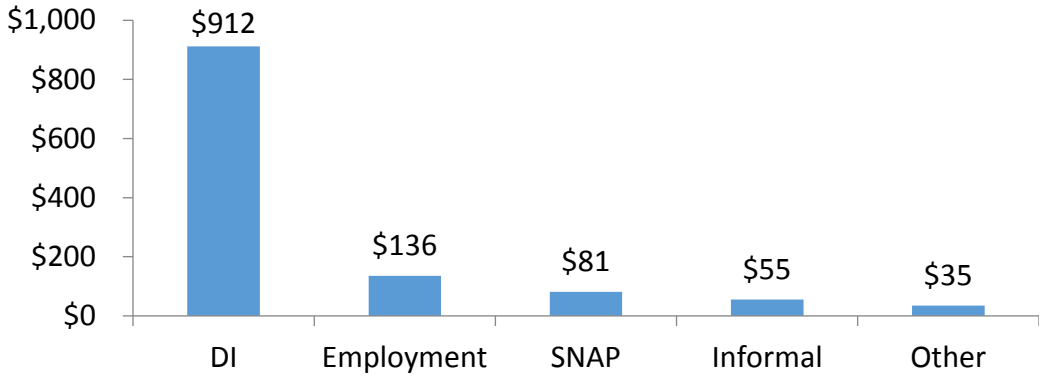


Study participants' average cash income by income category is shown in Figure 2.[10] The five income categories are DI, reported employment, SNAP, informal, and other. Informal

[10] The averages include participants with zero income in the category.

income includes unreported earned income and cash assistance from family or friends. Other income includes SSI and other means tested assistance. Participants' DI income ranged from approximately $500 to $1500. Participants 'average DI monthly income was $912 (SD $244) and this far exceeded the average incomes for the other categories. On average, DI accounted for 75% of participants' total cash income; employment accounted for 11%; SNAP for 7%; informal income for 5%; and other income for 3%.

Figure 2. Average Study Participant Cash Income by Income Category



To determine participant's poverty level percentage, we totaled participant's **formal income** including DI income, employment income and other income and divided by the poverty level. Sixteen participants had income below 100% FPL, 9 participants had income between 100% and 125% FPL, 7 participants were between 125% and 150% FPL, and 3 participants were between 150% and 190% FPL.

1. Employment Income

Six study participants were consistently employed. Their monthly earnings range from approximately $400 to $1100 per month and their average earnings were $742 (SD $261). On average among these six participants, their employment income accounted for 46% of their total cash income. The Massachusetts minimum wage at the time of the study was $11 per hour and these participants were paid the minimum wage or moderately higher. Two participants had income within $100 of the Substantial Gainful Activity (SGA) amount and they were careful to maintain their monthly earnings below that level. We did not assess participants' capacity to earn more than the SGA amount; however; one participant with income in the neighborhood of SGA suggested that his/her mental health limited his/her work hours.

> *I'm in recovery [mental health] and it's just hard for me to cope. And so, they gave me a part-time job where I can work 20 hours a week.*

Two study participants had occasional employment through a day-labor agency where they earned approximately $100 to $200 per month. Job seekers arrive at the day-labor agency early in the morning and if selected are transported to the job site for the day's work. Workers are paid the same day. One participant described his/her experience with a day-labor agency:

Its $11 an hour and we work about six hours max. So, it's about $66 with taxes taken out. I take home about $45.

2. SNAP Income

Twenty-eight study participants had SNAP income. Except for one SNAP recipient, all received SNAP benefits as a one-person household.[11] There was wide variation in SNAP benefit amounts and this variation also existed between participants with similar reported total cash income (excluding SNAP). The variation likely occurred because of variation in income types, housing costs, and housing status (homeless and not-homeless) across participants.[12] These factors are taken into account when determining SNAP eligibility and benefit amount. It is also possible that the variation occurred because of differences between the income participants reported to this study and the income reported for SNAP eligibility.

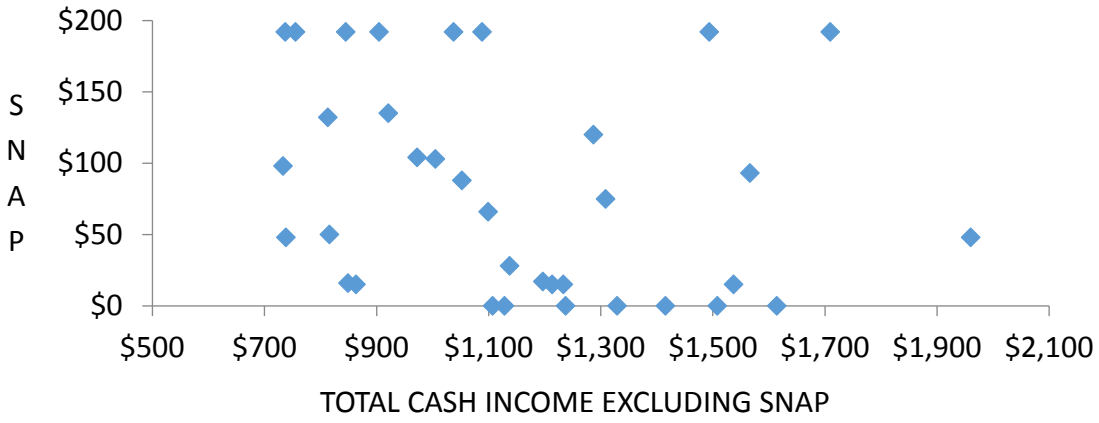
For the purposes of determining SNAP financial eligibility and benefit amount, a household is comprised of the people that are both living together and buying and preparing food together. SNAP benefit amounts are determined by net income and net income is based on several deductions, including deductions related to earned income, dependent care costs, medical expenses, child support payments, homelessness, and housing expenses. The benefit amount is calculated as the maximum allotment (e.g. $192 for one-person household) minus 30% of net income. States have the option to expand SNAP eligibility to provide a minimum allotment ($17) to households that would not receive SNAP benefits under the standards described above. Massachusetts expanded SNAP eligibility and provides a minimum allotment of $17 to one- or two-person households and this includes persons with disabilities that have a total income of less than 200% FPL.

The wide variation in SNAP benefit amounts among study participants and the relatively weak correlation (r = -0.35) between SNAP benefit amount and total cash income (excluding SNAP benefits) is shown in Figure 3. Seven study participants did not receive SNAP benefits; however, given their relatively low reported gross income it is likely that most were eligible for the $17 minimum benefit. Some of these participants reported that they previously received a $17 benefit but choose to not continue SNAP because the effort required to complete forms or report income changes. Six participants received the minimum benefit ($17). Eight participants reported receiving either the maximum allotment, $192, or an amount within $10 of the maximum allotment. Among these participants, their SNAP benefit accounted for approximately 15% of their total cash income. Fourteen participants received between $18 and $182 allotments. These participants received an average allotment of $89 (SD $37). For these participants, their SNAP benefit accounted for, on average, approximately 8% of their total cash income.

[11] For this persons, the SNAP benefit for the two-person household was divided by two.

[12] Persons that are homeless are not eligible for the SNAP shelter deduction; however, the homeless shelter deduction can be used to account for housing costs among the homeless.

Figure 3. Relationship between SNAP Allotment and Participant Total Cash Income[13]



The SNAP rules are complex; in particular, the rules relating benefit amount to household composition, housing expenses, medical expenses, income, and income types. We did not assess participants' understanding of the rules. However, one participant's description demonstrated his/her thorough understanding of the relationship between benefit amounts and income/expenses.

> *It's up to $192. They were cutting my benefits recently because they keep cutting people back. I was able to get highest deductible category because I have claimable medical expenses. I have supplies that I get and I pay out of pocket, even though insurance does cover some. I get better supplies by paying out of pocket. So that's how I manage to put receipts in and get the maximum allowable benefit.*

3. Informal Cash Income

Eleven participants reported informal income from unreported earned income and/or cash assistance from family or friends. Among the eleven participants, the average amount was $173 (SD = $180) and this accounted for, on average, 15% of these participants total cash income. Five participants described unreported earned income; this included braiding hair, house cleaning, parking cars, and collecting cans and bottles for redemption. The amounts ranged from approximately $50 to $200 per month for an average amount of $100 (SD $59).

> *I would say I collect cans maybe twice a week. If I do it all day, I can wind up with about $40 or $50 in my pocket. But that's all day. That's a lot of cans.*

> *Every now and then, I'll braid hair when I don't have money and that will give me $80 a head. I can do a head in about four hours.*

[13] For purposes of displaying the relationship and to protect the confidentiality of study participants, a random offset was added to income and to SNAP amounts that were not the maximum, minimum or zero. The correlation between SNAP amount and total cash income with the random offset is comparable to the correlation without the random offset -0.35 vs -0.32;

Nine participants received cash from families and friends ranging from approximately $20 to $650 per month for an average amount of $156 (SD $207).

I have had really close friends that are in my life and they help me...I had a friend that used to help me with cash and gifts and now he basically helps me pay my bills.

My mom helps me sometimes. She probably gives my about $75 a month.

I've been really stable and barely making it through the month. And many months, I've had to ask my brother for help at the end of the month. He helped me out a little bit here and there.

Some participants reported that assistance from family or friends was not available.

All my family is out of state and I know they have enough on their plate already. My friends are all in the same boat, unfortunately; so, it is tough to find anybody in my realm with money, especially toward the end of the month.

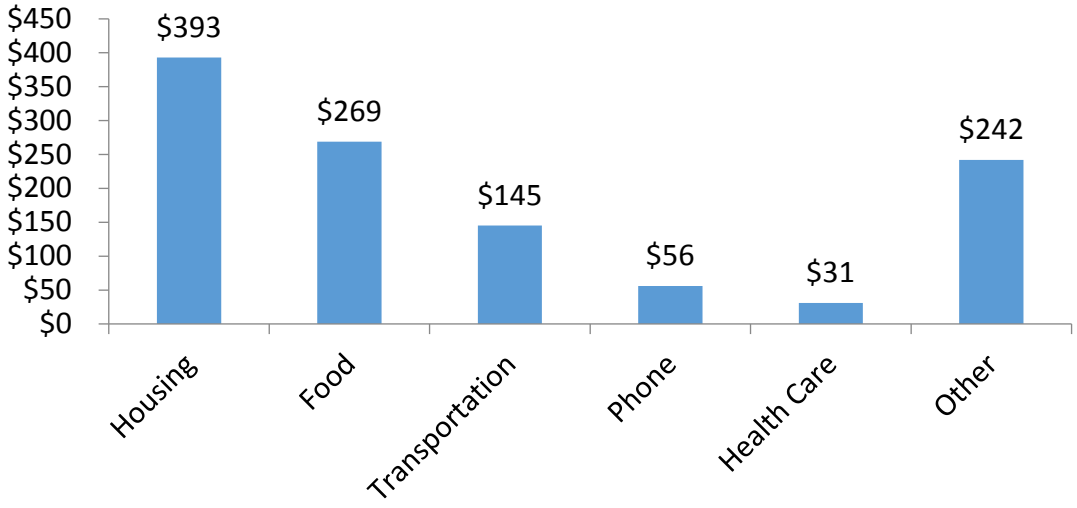
4. Other Cash Income

Other income includes SSI payments, veteran's assistance, and fuel assistance. Seven participants received other cash income ranging from approximately $25 to $400 per month and average other cash income was $175 (SD $140) among these participants. Three participants received SSI income, ranging from approximately $130 to $400. One person received veteran's assistance of approximately $300 per month. Three participants reported fuel assistance ranging, on an annual average, from approximately $25 to $80 per month.

I. Average expenditures

The average participant expenditures by category are shown in Figure 4. The average total expenditure was $1137 (SD $347). On average, housing expenditures accounted for approximately 35% of total expenditures and food for 24% of expenditures. Combined, housing, food, transportation, phone and health care expenditures were $895 (SD $361) and accounted for approximately 79% of total expenditures.

Figure 4. Average Participant Expenditures by Category



1. Housing Expenditures, Characteristics & In-Kind Income

Participant's housing expenditures were generally low. The average housing expenditure among study participants was $393 (SD $259). Seventeen participants had housing costs between $200 and $399 and 30 participants had housing costs of less than $600 (Figure 5). In comparison, the HUD 2018 Worcester fair market rents (40th percentile) for an efficiency, one-bedroom, and two-bedroom apartment were $850, $942 and $1,192 respectively.[14] On average, higher income participants had higher housing costs. The correlation between total cash income and housing costs was moderate (r=0.52) (See Figure 5). It is likely that this relationship exists both because people choose to spend more on housing at higher income levels and because rents for people that receive housing subsidies are tied to income, generally approximately 30% of income.

Most study participants found market rate rents to be unaffordable. Two homeless participants described their plans for affordable rent in the future.

> *Public housing is a three year wait at the very least so roommates are the only option. My own apartment would cost at least $650. That's not manageable. I could afford $500 or so.*

> *I have a couple of friends who said that they're checking with friends that rent rooms. One person did get back to me. And the person said that it will be $650 a month; I was like, that's out of my price range. I really need something ideally that's below $400 that has everything included. And that particular one was with cable, gas, electric, heat, everything was included, and even Wi-Fi. But, it was still beyond my price range.*

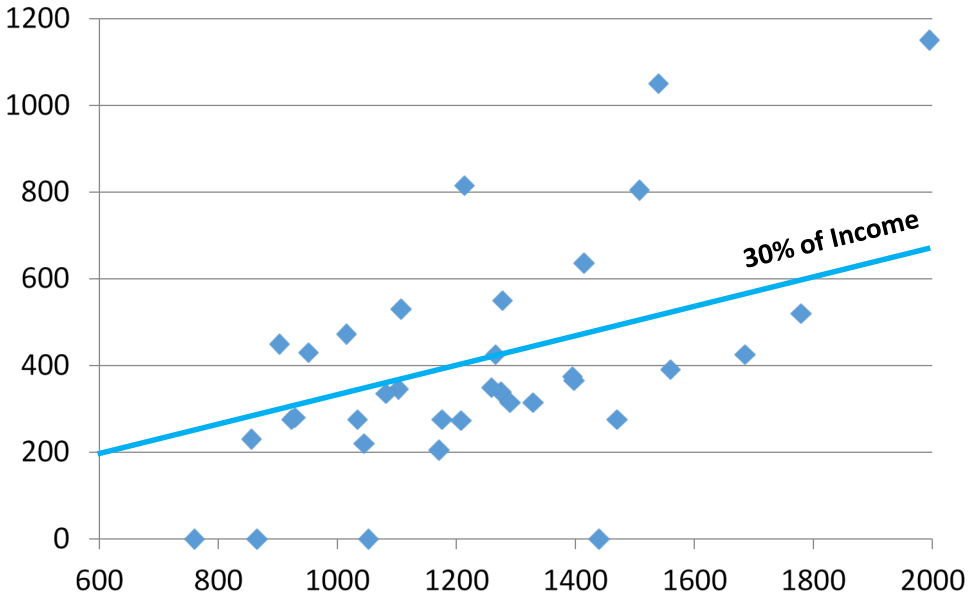
Study participants had relatively low housing costs because they were either: (a) receiving a public housing subsidy, (b) living in family (parents or siblings) owned property with below market-rate rent, (c) living with others, or (d) homeless (See Table 1). Eight study participants were homeless and living in or transitioning between shelters, motels, temporary housing for the

[14] https://www.huduser.gov/portal/datasets/fmr/fmrs/FY2018_code/2018summary.odn

homeless or apartments/homes of friends or acquaintances. On average, the housing costs for homeless individuals was $166 (SD $125). One participant who was homeless explained why he/she was temporarily staying at a motel:

> *Part of my Social Security retro check is paying for this motel. I really shouldn't use the check but at the shelter my medication went missing. If I don't have Suboxone, I go out and use [heroin] usually and that's not a good thing. It's better to be sober and pay a little more than to use and wind up paying more.*

Figure 5. Relationship between Housing Expenditure and Total Cash Income[15]



Two participants lived with their parents and one participant lived in a rental property owned by a sibling. The average housing costs for these individuals was approximately $400. One participant who was living in a rental property owned by a sibling explained the importance of low rent to making ends meet:

> *I'm getting by check to check. I'm not falling behind. If I was trying to pay my brother the amount of rent that I should be paying, I would be falling behind, but because he is lenient about the rent and because it's my brother, I don't.*

Fourteen participants received some type of public subsidy for housing where their housing payments were a percentage of their income, generally approximately 30%. The average housing cost for these individuals was approximately $345 (SD $81). Many participants currently living in market-rate apartments have applied for public housing and expected the waiting period would be long.

[15] For purposes of displaying the relationship and to protect the confidentiality of study participants, a random offset was added to the housing expense and total cash income.

I gave up on public housing -- I had applied and was on the waiting list at [redacted] for years. I had been waiting since 2011. Being homeless was the only way they said I could be moved up the list. I didn't turn in the paperwork after telling them that I was 'this close' to homeless. I guess because I had become demoralized, I didn't reapply.

A veteran who was formerly homeless and currently living in HUD Veterans Affairs Supportive Housing (VASH) was contemplating moving out of subsidized housing and into a market rate apartment. Because of a mental health condition, he/she reported that he/she was not able to live with roommates and described the expected budget changes.

I would say that my food budget and rent management are the two big issues. My rent now is fair. But once I leave here I'm again looking at living on $200 cash for the entire month. So I'm happy here but I am a little nervous about moving.

Eight individuals lived with others (not siblings or parents) in private apartments or homes. Housing costs for these individuals ranged from approximately $200 per month to $1100 per month and the average was approximately $557 (SD $283). An individual living with three others in a three-room apartment (2 rooms and a kitchen) and paying approximately $200 per month for rent and utilities described his/her living arrangement:

Q: You don't have your own room? A: No, I sleep on a little foam pad that's folded. It's good enough for me for right now.

Two individuals lived alone in market rate one-bedroom apartments**.** Their housing costs were high compared to participants living in public housing or living with others, approximately $800 and $1000. As one of these participants noted, the rent affected his/her ability to make ends meet.

Seventy percent of my income goes to rent. That's why I can't make ends meet.

Twenty-five study participants received in-kind housing income. In-kind housing income was received by the 8 homeless participants staying intermittently in shelters or short-term housing for the homeless, the 14 participants receiving housing subsidies, and the 3 participants living in family-owned housing. As a rough approximation, we estimated the in-kind income for the 14 participants receiving housing subsidies and the 3 participants living in family-owned housing as the difference between the fair market rent for a one- or two-bedroom apartment, depending on the living arrangement, and the participant's actual costs. Across all study participants, the average in-kind income for housing was $226 (SD $272). Among the 17 participants receiving in-kind income for housing, the average was $465 (SD $197); this compared to average expenditures of $355 (SD $85).

2. Food Expenditures

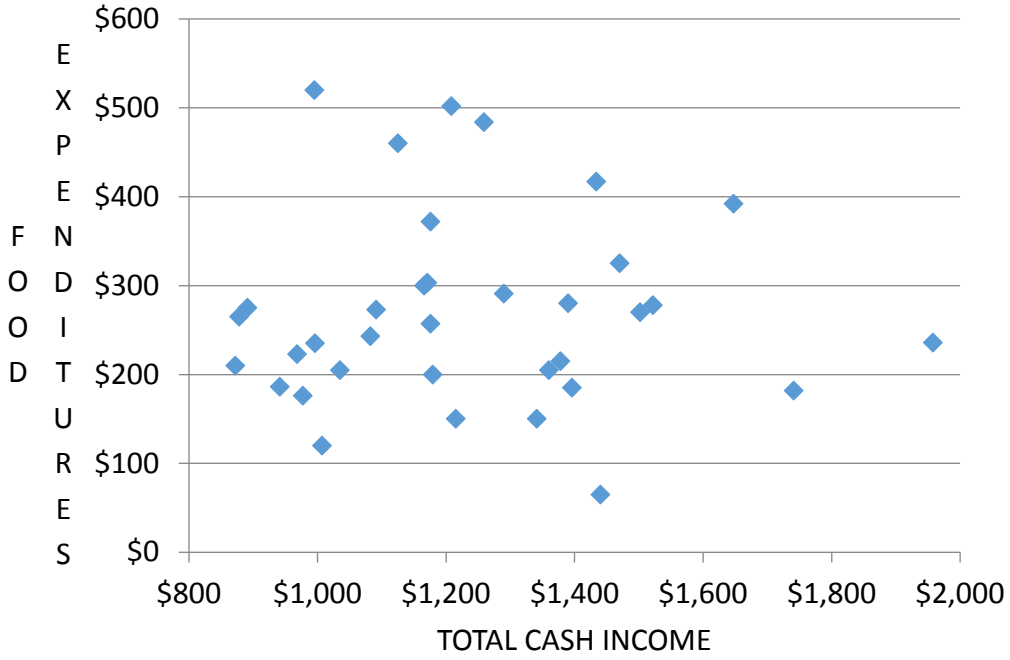
The average food expenditure reported by participants, including food purchases using SNAP, was $269 (SD $118). On average, 80% of the food expenditure was for food at home, $217 (SD $101). The average expenditures for food away from home was $53 (SD $71). For many participants, food away from home at restaurants or fast food establishments was not affordable.

I mean, having a Dunkin' Donuts cup of coffee is a treat that I don't get to buy. Someone will buy it for me eventually, but I don't ask.

The USDA estimates the monthly cost of food at home at four levels, thrifty plan, low-cost plan, moderate-cost plan and liberal plan and the estimated monthly costs are $186, $240, $300 and $365 respectively. Seven participants have total food expenditures equal to or less than the thrifty plan; 9 participants have costs higher than the thrifty plan and lower than the low-cost plan; 10 participants have costs higher than the low-cost plan and less than or equal to the moderate-cost plan; and 9 nine participants have costs higher than the moderate-cost plan (See Figure 6).

There was no simple correlation between monthly food expenditures and total cash income (r = -0.01) (See Figure 6).

Figure 6. The Relationship between Food Expenditure and Total Cash Income[16]



On average among all study participants, SNAP accounted for approximately 30% of food expenditures; however, there was considerable variation in SNAP benefit amounts and participation. Twenty-three participants received more than the minimum SNAP allotment of $17. Among these participants, SNAP accounted for 44% of their food expenditures.

Several participants reported other strategies they used to manage their food costs other than SNAP; these include food pantries, meals at community kitchens and shelters, meals with family

[16] For purposes of displaying the relationship and to protect the confidentiality of study participants, a random offset was added to total cash income.

or friends, and purchasing food at reduced costs because it is nearly expired or will be discarded (e.g. end of day at McDonald's). Except for participants that were homeless, these strategies were not used frequently.

> *I even actually asked if they are throwing food away because it's on the expiration date -- if I could buy that food. And sometimes -- it depends on who is working. They will let you buy that food for dirt-cheap. All you have to do is refreeze it before it goes bad.*

3. Transportation Expenditures

Participants' average monthly transportation expenditure was $145 (SD $160). There were 10 participants that owned cars and their average transportation expenditure was higher compared to participants without cars, $362 (SD $122) vs. $58 (SD $53).[17] As expected, participants that owned cars had higher total cash income compared to other participants, $1436 (SD $287) vs. $1131 (SD $216). In addition to cars, participants used a variety of transportation methods including: public transportation, informal paid rides, UBER, taxis, Medicaid medical transportation, rides from family and friends, bicycling, and walking. Many participants reported purchasing monthly 'Charlie Cards', a Worcester Region Transit Authority pass for $28.50, a reduced rate for people with disabilities.

> *I do a lot of walking, mainly. If they want me somewhere, I'll just walk. I have the time and it doesn't cost anything to walk.*

> *I have a car, and it's very, very old, and I drive it rarely, because if I get a monthly pass on the [city] bus line it comes out for me cheaper than driving the car. So, I take the bus a lot, and I just use the car if I have to go outside of [city]. But the car is very iffy. Any day it could just break down, and if that happens I have no money to be able to buy another car.*

Participants also reported in-kind income for transportation; these include medical transportation, rides from family or friends, borrowing a car from family or friends, or subsidies for transit passes.

4. Phone Expenditures

All participants had cell phones and most had smart phones. The average phone cost among participants was $56 (SD $37). For most participants, the expenditure covered their individual phone plan. In some cases, the expenditure also included services for others (e.g. children) or other services (e.g. internet). Four participants received no-cost or reduced cost cell phone services through the Lifeline Program for Low-Income Consumers. For several, primary access to the internet was through their phone. Two participants reported that family or friends paid for their phone plans.

> *I only have internet on my phone and only if there is Wi-Fi. I have trouble seeing the screen and it is a very cheap one. It is a smart phone but it doesn't work.*

[17] For car owners, the transportation expenditures did not include depreciation expenses.

5. Health Care Expenditures

Participants' expenditures for health care were low and averaged $31 (SD $51). Nearly all participants were dually eligible for Medicare and Medicaid. With this dual coverage, participants reported only incurring health care expenditures for prescription co-payments ranging from approximately $1 to $3 per drug. For these participants, the Medicaid program pays for Medicare premiums, copayments and deductibles via the Medicare Savings Program. Only two participants reported expenditures for Medicare premiums, copayments or deductibles. One of these appeared to have income that exceeded the Medicare Savings Program limits. The other participant reported temporarily losing Medicaid coverage for an administrative reason. These two individuals had substantially higher health care expenditures compared to the average.

6. Other Expenditures

Other expenditures included expenditures other than housing, food, transportation, phone and health care. These included expenditures for alcohol, marijuana or illicit substances, contributions to church, credit card interest, cable/internet, clothes, contributions to family members (parents siblings children), gym memberships, life insurance, loans or debt payments other than car loans, personal care or household items, storage, and tobacco products. The number of participants that reported other expenditures by type is shown in Table 3. The amounts of these expenditures varied considerably across participants (See Figure 7). Across participants, the average other expenditure was $242 (SD $226). There was no apparent correlation between total other expenditures and total cash income (r = 0.05).

Participants also reported in-kind income for other expenditures. This includes receiving the following from family or friends: cable/internet, clothes, and personal care or household items. Participants also reported receiving clothing from community-based organizations

Table 3. Number of Participants Reporting Other Expenditures by Type

Other expenditure type	n	Other expenditure type	n
Alcohol, marijuana or illicit substances	4	Gym memberships	1
Contributions to church	1	Life insurance	3
Credit card interest	7	Loans or debt payments other than car loans	2
Cable/internet	14	Personal care or household items	15
Clothes	8	Storage	6
Contributions to family (parents, siblings, non- custodial children)	3	Tobacco products	12

Figure 7. Relationship between Other Expenditures and Total Cash Income[18]

J. Month-to-month budgeting

Nearly all participants reported approximately balancing their monthly income and expenditures without any substantial monthly savings or debt. Only one participant reported using an asset—home equity—to pay for current consumption. One participant also had substantial prior credit card debt but was not paying for consumption with credit at the time of the study. Participants described balancing income and expenditures:

> *I'm always worried about money. I only get a check once a month. So I have to stretch it out all month long. Usually, by the end of the month, I have no money. I'm waiting for the next check to come in.*

> *There's no room for savings because every month, everything goes. I really don't want to live out my years with only social security because it's just not enough*

While most participants reported an approximately balanced monthly budget without savings or debt, six participants reported monthly savings, often targeted for a specific purpose, for example, travel to visit family, a vacation, or purchase of a car. The six participants reported monthly savings and savings amounts ranged from approximately $40 to $250.

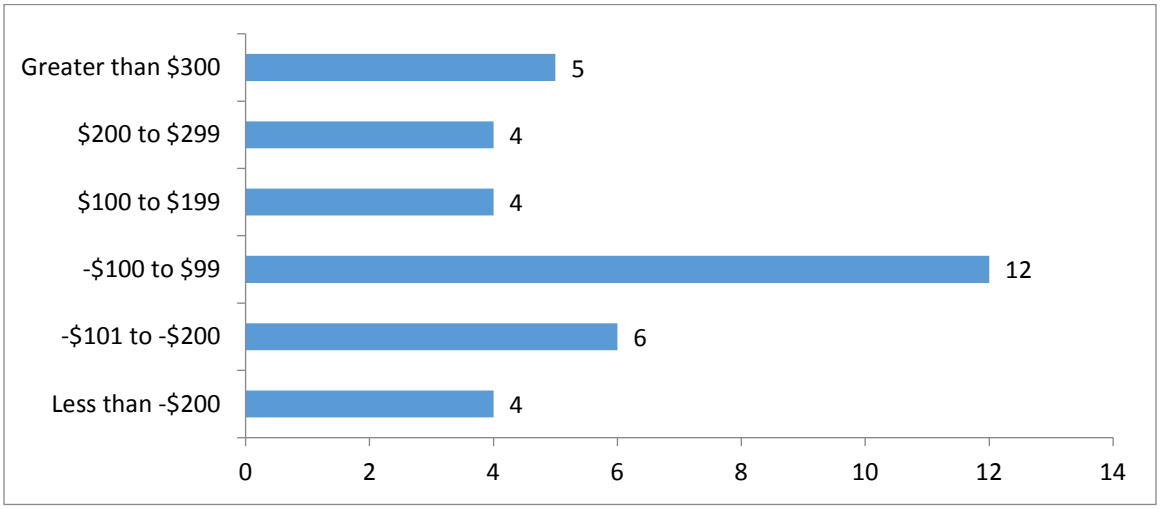
> *I save two or three hundred dollars every month. I go to the beach every year for a 3 day vacation.*

[18] For purposes of displaying the relationship and to protect the confidentiality of study participants, a random offset was added to total cash income.

Sometimes I'm able to put aside like $100. And sometimes I'm not able to, because I go and buy something that month, like clothes, then the budget becomes really tight.

While nearly all participants reported that their total income and expenditures were approximately balanced each month, there were differences between the total reported monthly income compared to the total reported monthly expenditures and savings (See Figure 8). On average, study participants reported $54 (SD $211) more in monthly income compared to monthly expenditures/savings. This was expected because the interviews focused on major expenditures. Minor expenditures, for example personal care or household items were less often discussed or reported. The reported budgets (monthly total income minus monthly total expenditures and savings) of 22 people were within plus/minus $200 and we consider this to be more or less balanced for the purposes of this study. There were 9 participants with reported income that exceeded reported expenditures/savings by more than $200 and 3 people with expenditures/savings that exceeded reported income by more than $200. We do not know the reasons for the discrepancies.

Figure 8. Monthly Total Income Minus Monthly Total Expenditures and Savings

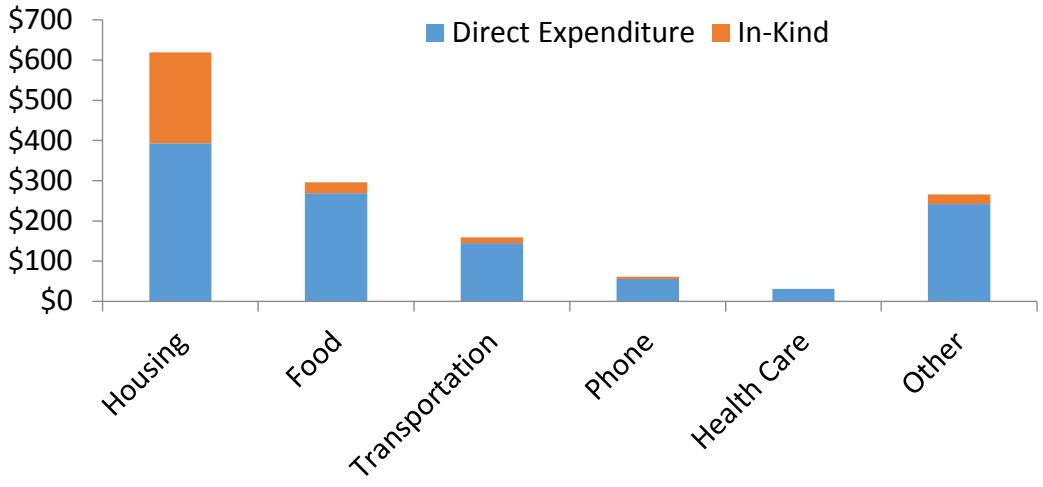


K. Total consumption

As discussed above, both expenditures and in-kind income supported participants' consumption. The average housing expenditure was $393 and this compared to the average in-kind income for housing of $226. The average expenditure for food, transportation, phone service and other was $712. Participants received in-kind income for these as well. With a few exceptions, participants reported these in-kind contributions were relatively infrequent and not a major component of their consumption. For example, a family member or friend paying for a phone plan, paying for a movie ticket, buying clothing, lending a car for day, or buying household items. Based on participant's descriptions, we expect that the in-kind income would be approximately 10% of participants' food, transportation, phone, or other expenditures. Hence, we estimate the in-kind income for these categories to total $71. Combining this with the average in-kind income for housing, the total is $297.

Considering both expenditures and in-kind income, participants' average consumption was $1434 ($297 + $1137). In-kind income accounted for 21% of consumption and expenditures accounted for 79% of consumption (See Figure 9). This allocation of consumption considers SNAP as income used for food expenditures, consistent with the preceding sections of this paper. Treating SNAP as in-kind income changes the allocation to 26% in-kind and 74% direct expenditure.

Figure 9. Study Participants Average Consumption



L. Consumption adequacy

Study participants were asked if they experienced hardships in the various consumption categories. That is, whether they were able to meet their basic needs for healthcare, food, transportation, and housing. Except for dental services, nearly all participants reported that they adequately met their needs for health care through Medicare and Medicaid. Most participants reported that they were satisfied with their healthcare services and that their consumption of these services was not limited.

I get the best health care... It's everything I need

I have MassHealth[Medicaid] and Medicare. I'm getting everything I need.

A few participants reported limited access to dental services because of the limited services covered by fee-for-service Medicaid and their inability to otherwise pay for dental services.

I have cavities and I am just buying time. I am just hoping to hold out until I'm able to get to a spot to where I can address it.

A few participants reported having One Care coverage, the Massachusetts program that integrates care for working-age beneficiaries who are dually eligible for Medicaid and Medicare. One Care covers a broader range of dental services compared to fee-for-service Medicaid and One Care members reported better access to dental services.

When I was on One Care -- the few months that I was on it -- I had my dental care taken care of, and that was a huge help.

Participants' reports of food adequacy varied. Nearly all participants reported some limitations, for example not being able afford the types or quantities of fresh fruits and vegetables or meat that were desired or not being able to afford restaurant meals, including fast-food restaurants.

I would eat fresher vegetables and fruits if I could get them, yeah, they're off the table with this budget, really.

There's not a lot of fat. I mean I don't go out to eat. My luxury is going out to eat and getting a five-dollar pizza and that's only the low price on Monday through Thursday. It's the cheapest pizza you're going to get.

Approximately one-quarter of participants reported more severe food limitations, for example skipping meals or severely limiting the types of food they consume. For example:

I buy all the cheapest food I can get, like Ramen noodles and stuff like that. I don't have meals-- I can't afford meals. Meat is very expensive. I actually go without food at times, maybe for four or five days at a time. I just don't have the money.

It's just food is expensive and food stamps go fast. First 15 days and then I am broke. I just get a couple jars of peanut butter and I live on bread. I guess Cream of Wheat pulls me through. I love that Cream of Wheat anyway.

I'm not getting as much as I need. For example, I don't eat breakfast anymore because I don't have that much money. Yeah. So, I just skip breakfast and do lunch and dinner.

Participants reported that they had good access to community resources, for example food pantries, food banks, and community meals to meet their food needs when necessary.

The city has a really good network of free meals. I was really surprised by that. If you're homeless in this city, you shouldn't be hungry.

Food is limited, but not a hardship. There are many services. I have food stamps. I am only one person. The older you get, you eat differently. There are food banks, which I never really had to use, because I make it work for me. Somehow, it works.

I know that Worcester probably has one of the best, in Massachusetts, probably on the entire east coast, food pantries that help out once a month. I think they give you a fair amount of food.

Except for study participants that were homeless, participants did not report hardships associated with their current housing. Participants generally described their housing as adequate and some described overall satisfaction with their housing as did these two participants living in public housing.

No hardship. I mean, public housing has been a total blessing for me in terms of stability. It's also, in a way, kind of a trap for me. I think of my life becoming more functional. What if I want to move somewhere? I'm kind of anchored to this place. Being anchored is a nice thing -- it's stable and steady.

It's safe. It's clean. And it's well managed. I mean, I hear a lot of stuff from the older folks who have been here longer than I have. They complain. But it's my first one-bedroom.

Twenty-five participants did not own cars and relied on a combination of public transportation, taxi/Uber, or rides from family or friends. There were transportation limitations reported among these participants.

But a lot of times, I'm stuck at home, because I don't have any money to do anything else and there's not a lot of transportation on Saturday. So that, I think, would be a big help.

Because I don't have transportation, when I go to the market, I do all of my shopping at one time. So a lot of what I buy is either canned goods or frozen foods. I am not getting fresh food using a lot of frozen stuff, canned goods.

Ten participants owned cars. Participants reported that they could not afford car maintenance costs.

I have to borrow money from somebody because I need to go have an oil change in the truck.

I can't afford a tune-up. And it has a bad tire which I can't replace. So that reduces gas mileage. I have to pay a dollar to a dollar-fifty in every couple days to put air in.

Most participants reported that their budgets were very tight and there was little money available for 'extras.'

Clothing, I could definitely use some new clothing but don't have the money for it. Yes, that's definitely a problem. Even buying a pair of shoes, I don't have the money for that.

I need a new couch; I need a new bed. My bed is broken. I've been sleeping in it for the past eight years. The bed is broken. It goes this way. It goes down, so I'm sleeping in a very strange position all the time. The couch is terrible

I need a CD player right now, because I'm in a choir at church, and I don't have a CD player to practice the music. So I can't even go buy one -- even if it is $20, I don't have it.

One participant described the items or services he/she would purchase if the money was available.

Strange to say, but I would take a yoga class, which is really good for me, mentally, socially, and physically. I would go out to a restaurant meal. Oh, I know. Two big things: I would get my computer back and I would subscribe to the local newspaper again. I miss them very much. I would download music and listen to music. I'd be able to listen and go I'd buy a new pair of glasses so I could see the computer better. I'd buy splints for my hands. What else? I'd -- yeah. I'd buy over-the-counter medicine for things. I can't really afford those,

either. What else? I don't know. I'd stop collecting bottles. Yeah. I'd have a -- hopefully a better social life. I wouldn't be as depressed and frantic all the time.

One participant who experienced a decrease in consumption as a DI beneficiary compared to a period prior to DI when working, described the change:

Before DI I used to go to the store and get what I want. Now, I have to be very selective. When it comes to the groceries I go look at the carts that have items that are marked down. It's good but you still look at the date. This is what you got to do in order to survive. When I go to the clothing store, instead of going to the regular racks, I go to the clearance rack. Have they marked down anything? I look at stuff, I pray about it, I say, "God, you need to mark that down. I need to get it lower than that." I say, "You know how much money I have in my pocket." And then I will leave it there. When I come back, if it's for me, it will be marked down.

M. Homeless participants

Eight participants were homeless at the time of the study. The living arrangements homeless participants reported included homeless shelters, short-term housing for the homeless, motels, hospitals, and short-term stays with acquaintances, friends or family. Several homeless participants reported multiple living arrangements over the short time period of the study interviews. Interviews were conducted in the winter and there were no participants that reported living outside or living in cars at the time of the interviews.

We did not assess the reasons why participants were homeless; however, participant descriptions suggest that homelessness was, at least in part, associated with the high cost of housing relative to income, difficulty paying the up-front costs (first/last month's rent and security deposit), difficulty securing housing because of poor credit rating and/or criminal record, and inability to navigate the processes necessary to secure private or public housing.

I was denied subsidized housing. My number came up on the list. I had the meeting with the lady and everything looked good. And then, I got a letter from her with my entire CORI [Criminal Offender Record Information] attached to the letter, just saying that I had been denied housing.

Right now I am in-between apartments. I'm looking to move in somewhere on the first, but it's not guaranteed. Unfortunately, it's not easy to come up with first, last, and security. You have to live month-to-month. So, unfortunately, our options are limited and so what we try to do find friends that already have apartments and that would be willing to rent out a room in their apartment for, you know, roughly $500 to $600 or so a month.

Landlords do credit checks, so, on paper, I don't look the greatest. It's tough for somebody to give me an opportunity.

Participants reported numerous hardships associated with being homeless including stress, theft, and adverse effects on health.

The most challenging part of bouncing around like I do is keeping my stuff. Basically, I am carrying around a bag or two with all my important possessions. I have to guard everything. If something happens to my medications I run out too soon.

Being homeless drains you, mentally, physically, spiritually, psychologically. It drains you; the lack of sleep. Sometimes you have to rough it and sleep in places where you're not too comfortable sleeping, like basements or somebody's vehicle. If times get really rough and you don't know what else to do, you try your best to avoid bad situations.

I've been robbed, I think three times since I've lived here. So in seven or eight months I have been robbed three times. Once it was a gun, I'm not sure if it was real or not. Then another time it was one guy with a knife, and the third time it was three guys that were strong-arming me, like whatever, I told them to just take it.

My frostbite is from having a bad fall and knocking myself out. When I woke up snow was all over me and I brushed myself off, and I went to the shelter. The next morning, I looked at my hands and they were swollen. God, they were swollen. I went to the ER, and they said, "What are you here for?" I just held up my hand, frostbite.

Participants reported that overnight shelters were readily available. Most homeless participants reported staying at shelters as a last resort because of violence, theft, and exposure to drug and alcohol use.

There have been a few fights but I have not been involved in any of them. Now there was one guy that was taken and arrested last night and he hasn't come back yet. If you're a person that can't control their own emotions and reactions to people, it's a very difficult environment. That's why there are so many temper flares and so many arguments and beefs over this, that and the other thing.

I went to the shelter before. They were trying to steal my shoes, right off my body. They'll go underneath your pillow. They'll take anything around you that they can. They will steal whatever you have. It's ridiculous.

Obviously, it is winter, it's a wet shelter so that means that everybody's doing drugs or they get drunk. I am a recovering person -- I've been sober for five years now – going to the shelter makes me want to relapse sometimes, being that depressed and being in that situation with everybody around me doing drugs. It's a very difficult situation for me.

Even though we did not specifically ask non-homeless participants about prior periods of homelessness or housing instability, an additional 9 participants reported prior periods of homelessness and an additional 6 participants reported prior periods of housing instability because of evictions or difficulty finding stable housing.

I ended up homeless. I ended up evicted. And it was one of the most traumatizing things in my life. And, I've actually experienced it two more times since.

I had surgery on my neck and recovered in my vehicle. My cousin's girlfriend had a meltdown and threw me out and I still went for the surgery. I needed it. I couldn't even lift the blanket, it was bad. And I didn't tell the doctors because then they wouldn't have done the surgery. I was going to play that game. I recovered in my vehicle.

In February, I will have been in this apartment one year. It took me eight months to find this place event though it is expensive. When the landlord sent me the letter that I had to move I was freaking out. I thought, oh my God, I'm going to lose my place. I'm going to be

homeless and have to live in my car again. I'm just really too old for that, you know what I mean?

A few participants explained that being homeless improved their access to housing and other needed services.

I used to live with my brother and then we went different ways. After that, I had a one-bedroom apartment, but it ended up being too much money for me. I actually became homeless after that because I just couldn't pay the rent. And when that happened, that's when I got a lot of the help [subsidized housing and a case manager].

The shelter does help people with housing, but it takes a long time.

I went down to Housing Authority. They said it would be a one- to two-year wait. Although someone here told me, not the staff though, so I shouldn't put a whole lot of stock in it, that you put this shelter down as your address and you will get to the top of the list more quickly. I want to ask the caseworker about that.

N. Other hardship circumstances

In addition to hardships described above associated with poor health, low consumption levels, or being homeless, participants reported other current or prior hardships, including loss of custody of children, social isolation, suicide attempts, substance use disorders, drug overdoses, and incarceration. Thirteen participants reported one or more of these circumstances at some point in their adult lives.

I had multiple suicide attempts and hospitalizations-- like 10 hospitalizations in [year] in the psych unit. I was in the ICU for like, two separate times for a total of like 20 days.

I've only just started becoming a little more functional. I mean, I was basically a shut-in for more than 15 years. I would only leave the house to go for medical appointments and food shopping, basically, if I had to. I had become extremely unfocused, and, you know, massively depressed, and zero self-confidence.

And, you know, there were bad things with drugs coming into our lives and we had problems and issues with that and that left us without anything to eat.

I've had struggles in the past with chemical dependency, so I have been to jail.

My children live with my mother. I sometimes think if I had money I would be able to take care of them, but probably not with my mental instability. That's what they said when they did a psychological evaluation on me. They said that since I recognize the fact that I'm not consistent with being mentally clear and I have problems, they're better off living with my mother.

O. Participants' future plans

We asked participants about their expectations for future participation in DI. Four participants expected to exit DI and were actively taking steps toward a future exit. The steps

varied. The first participant was completing a college degree and planned to soon start searching for full-time employment.

> *No, I'm not feeling trapped at all. I want to work. I want to get off benefits. So, my plan is to get a job in Boston. I will have to take the train. That is going to be $100 a week, round trip. At the end of six months, hopefully I will have enough money to buy a car so I can drive part of the way and take the T [train/subway] the other half. Eventually I plan to have enough money to rent an apartment just outside of the city, on the T line*

The second of these participants, who in recent years maintained part-time employment while a DI beneficiary, was interviewing for jobs. This participant planned to work part-time for a period and then transition to full-time work, with the hope of working 40 hours per week and earning $17 per hour. This participant's planned future budget included new expenses for private healthcare insurance, the purchase and maintenance of a car, private market rent and first/last month's rent. As part of the planning process, he/she met with a Work Incentive Planning and Assistance benefits counselor and understands the DI work incentives and indicated that the Extended Period of Eligibility was an important component of his/her transition plans.

> *I already talked to someone about that. I can get off Social Security and I will have a waiver for three or four years so if it doesn't work out within three or four years, then I can automatically transfer right back to Social Security.*

The third participant was a young adult with a history of multiple recent psychiatric hospitalizations and a substance use disorder. He/she planned to exit DI once he/she achieved more stable mental health and a substantial period of abstinence from substances. At the time of the study interviews, the participant was transitioning to a 'sober house' that required substance abstinence.

> *I hope to not be on SSDI that long. That was the general idea, just for a short-term crutch. To give me the ability to get stabilized with the other things, and then go back to work. Six months, and then I'm planning to relocate to [another state], I think. At this point, that's my tentative plan, but that's assuming everything's going well and I'm doing decently. My dad will give me cash work out there. So I can work for cash and get back on my feet a little bit and housing is cheaper out there as well.*

The fourth of these participants, a person with paraplegia, plans to work part-time to pay off current debts and to complete his/her college education. This participant's prior college participation was interrupted by an injury that resulted in paraplegia. In recent years, the participant has maintained consistent part-time employment.

> *I understand it is difficult to get back on DI if I leave so I plan to continue work part-time. My plan is to pay off all the debts that I owe and then go back to school and then get a full-time job. When I'm in school, I won't be able to work full time. Actually, I used to, when I was walking. Now, it would be hard for me to work full time at the same time as being in school.*

In additional to the participants that planned to exit DI, a few participants reported that short-term employment at wages that support self-sufficiency may be obtainable. However, many participants reported that long term job stability was unlikely because of the instability of

their health and/or the instability of the jobs. Participants were concerned that if they exited DI for employment and later lost their job, it would result in financial hardship.

I might be able to get the job, but then as far as keeping it, who's going to keep me if I get sick. I've been home sick for four weeks after I came out of the hospital. If I had a job, they would have let me go. Those are the thoughts that go through my head. And then, what would I need to do to get back on Social Security, I have to go back through all those things again -- the denial, the stress. It almost drove me crazy. Crazy, you know? It was a lot mentally.

I go back and forth from -- that I'm just going to just grab any work -- just a little bit and not threaten my benefits and just see how good I can do -- to the extreme -- I'm going to get the fulltime job and I'm going to sink or swim. I probably will fail. If I look at my whole work history, I had interpersonal problems in every job I had. I can imagine that those things could even be worse now, so who am I kidding?

I would like to, but I feel trapped. Unless I found a good, stable, secure job with stable hours and full benefits -- including health benefits -- I'd be afraid to step off Social Security.

Except for the four study participants that were taking steps to exit DI, the other study participants were not planning to exit DI. We asked the 26 study participants that were not planning to exit DI and were not currently employed about their plans for employment. As we describe below, we grouped participants into the following labor force statuses: interviewing (n=2), searching for a job (n=8), volunteering (n=2), contemplating employment (n=10), and unable to work because of health or disability (n=4).

Two participants recently lost jobs and were interviewing for new jobs. One of these participants was confident that he would soon receive a job offer as a delivery driver. The participant reported that he/she planned maintain his/her income below the SGA amount.

The job is going to be 20 hours a week for $11 per hour. They said it would be 20 to 25 hours per week, but I can't work 25 hours. I'll lose disability then. I can't make more than $1170 gross a month. If take a full-time job and I fail, I will lose everything. I lose all of this. It's not practical with my disability. I have a psychotic disorder. It's hard for me to maintain full time employment.

Eight participants reported that they were actively looking for work. The intensity of the job search varied across these participants.

I've been looking for past 10 or 12 years, no one is hiring me at all.

Yes. I was looking for a job. I've been looking for a job for the last couple months and I just haven't had any luck.

Two participants with college degrees were volunteering in positions at responsibility and hourly levels comparable to paid positions. The first of these participants with a severe physical disability and professional skills had previously terminated DI and subsequently returned because of a layoff. After an extensive job search, he/she has not been able to secure comparable employment in his/her profession and is no longer seeking paid employment.

Trust me, during those six years of unemployment, I tried every local firm. I tried everyone. I said 'Do you need work done on the side? Will you contract work out to me?

The second of these volunteers who has physical and cognitive disabilities related to an injury has been hired many times but has not been able to maintain stable employment and is no longer seeking paid employment.

So I went to the job and they trained me for two or three weeks. I knew what to do but there was just too much going on at one time, with my half brain that I'm working with. Using just one hand I had to count out money. It was very difficult. So, I was giving people the wrong change and in return, I was losing money out of the register. It was crazy. It wasn't a fit. But I was there every day. I liked working, you know. I was busy, so I liked it. When I'm working, I love it, because I stay busy. But I need to find something I can do, physically and cognitively.

Ten participants were contemplating employment. They expressed concerns about their employability, their needs for accommodation, and the effect of their health or disability on their ability to secure and maintain employment.

I imagine what it would be like to actually do a four-hour shift at like, a store or something. I have no idea what it would be like. Maybe it would be fine, maybe I would just be ridiculously exhausted part way through it. I don't know. I have no idea. Maybe I would have a panic attack or have social issues or something. I don't think I would but it's hard to say.

I'm going to apply to [local retail store]. They probably need help. But I have to quiet down first. I have to get more stable.

Right now, I am interested in anything I can physically do. I can't do fast food with my back and everything else. I can't physically do that kind of work. Trying to find something my body would physically be able to do and them hiring me.

It's difficult, because for example, I can't even do Papa Gino. I can't even do McDonald's. I can't do housekeeping anymore. Cashier -- I was working cashier before and that won't work now because I'm not going to be fast. They want people to be fast doing that type of job and I don't have the ability to be fast like before. It would have to be something like the monitor in the bus -- the yellow bus for the kids from Head Start. Something like that, maybe.

Four participants reported that they were unable to work because of their health and/or disability.

I can't physically work anymore.

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IV. LIMITATIONS

The findings of this study are based on the experiences of 35 low-income DI beneficiaries and cannot be generalized to the national population of low-income DI beneficiaries. The participants were not randomly selected and the characteristics of the participants differed from known characteristics of the national population of low-income DI beneficiaries; the study participants were younger, had higher education levels, included a higher percentage of men, and had higher participation in Medicaid. Given the high level of Medicaid participation we expect that study participants' health care expenditures were lower and their access to healthcare services was better compared to the national population. We do not know how differences in age, education, percent male, and living arrangements may have affected how study participants made ends meet compared to the national population.

Approximately two-thirds of study participants either received housing subsidies (public or family-based) or were homeless. We are not aware of estimates of these percentages for the national population of low-income beneficiaries. The participants all lived in the greater Worcester, Massachusetts area. Participants in other areas may have different experiences because of differences in local area cost of living or access to services. Study participants reported good access to local assistance for basic needs (food, clothing, and emergency shelter) and social services. Low-income DI beneficiaries living in areas with less access to these services may have greater difficulties making ends compared to the study participants.

The findings are based on self-reported data and there may inaccuracies in participants' reported information. To address possible major inaccuracies in reported income or expenditures, we attempted to reconcile total expenditures and total income (at an approximate level) and asked open ended questions when these did not more or less balance. We did not find major discrepancies reported total expenditures and income. In addition, we interviewed approximately 26 participants at their residences. We found that participants living situations, for example quality of their housing, were consistent with their reported income and expenditures.

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V. DISCUSSION

This study assessed how 35 low-income DI beneficiaries living in the Worcester, Massachusetts area made ends meet. We found that participants used their formal income to support most of their consumption and thus, consumption levels for most participants were low. Participants also accessed other resources to support consumption. Nearly all participants accessed healthcare services through Medicare and Medicaid with minimal out-of-pocket expenditures. Public housing subsidies accounted for approximately 34% of participants' housing consumption and SNAP accounted for approximately 27% of participants' food consumption.

Participants' descriptions of their financial situation were consistent with low levels of consumption. Nearly all participants reported living month-to-month without accumulating savings or debt. Most participants reported that they were 'just getting by' or 'finding it difficult to get by'. Given the high costs of market-rate housing relative to participants' income, all participants maintained low housing expenditures, on average $393 per month. Among participants that lived in market-rate apartments, nearly all lived with roommates to control their housing expenditures. For these participants, living alone was not a viable financial option. Eight study participants were homeless. Participants' average food expenditure was $269 and 80% of the expenditure was for food at home. Twenty-five participants did not own cars and their average monthly transportation expenditures were only $58.

What was participants' material wellbeing? Wellbeing is subjective and we based our findings on participant self-reports of consumption adequacy. Nearly all participants reported good access to healthcare services and satisfaction with Medicare and Medicaid covered services. For homeless participants, their consumption of housing was clearly inadequate and they reported it at such. Participants that were not homeless generally described their housing as adequate. Reports of food adequacy varied with most participants reporting at least some limitations in the quality and quantity of food they consumed although the severity of the reported limitations differed. Approximately one-quarter of participants reported more serious limitations, for example skipping meals or having very limited food quantity or variety at the end of each month. Twenty-five participants did not own cars and this limited when and where they could travel although this did not appear to result in severe limitations. Participants reported that they were able to meet their essential transportation needs, for example medical appointments, food shopping and employment.

Given participants low and sometimes inadequate consumption, how can consumption be increased? One possibility is increased employment. Only 4 study participants reported that they were unable to work and this suggests that increases in employment may be possible. Social Security Administration (SSA) work incentives and employment supports focus on DI beneficiaries' eventual self-sufficiency. As described in the SSA Red Book (2018): "The SSDI employment supports provide help over a long period of time to test your ability to work, or continue to work, and gradually become self-supporting and independent." For those low-income beneficiaries that have attempted self-support through employment without success and do not have plans to exit DI, the focus on self-sufficiency may not resonate and may not elicit employment. A focus on employment at levels below SGA to improve material wellbeing, concurrent with DI participation, may be more effective among these beneficiaries.

Consumption could also be increased through higher DI benefit amounts. DI benefits are progressive and among beneficiaries with a history of very low earnings, DI benefit amounts are comparable to their prior earnings levels. As a rough approximation, DI beneficiaries with average prior earnings of less than $856 per month receive DI benefits that are approximately 90% of their average prior earnings. Thus, relative to average earnings prior to DI, these beneficiaries do not experience a large drop in income. Nevertheless, as this study demonstrates, these low benefit levels only support low levels of consumption. Changing the DI benefit formula to provide DI payment amounts in excess of average prior earnings would help to support additional consumption. For example, a minimum DI benefit equal to 100% FPL would provide additional income to 26 of the study participants.

Also, consumption could be increased through increased targeting of means-tested support to low-income DI beneficiaries. She and Livermore (2007) found that material hardship was more severe among persons with disabilities compared to persons without disabilities after controlling for income, socioeconomic and family characteristics. The reasons for the difference are not fully understood. Compared to people without disabilities, people with disabilities may have less access to informal income, for example help from family or unreported employment, and/or may need more resources to meet their basic needs, for example, they may require more resources to meet their basic health care or transportation needs. Regardless of the reasons, the She and Livermore (2007) finding suggests that taking disability status into account when determining eligibility or calculating benefits for means tested programs would help to alleviate the higher levels of hardship experienced by persons with disabilities. As an example of this, SNAP has several rules specific to persons with disabilities that are favorable to persons with disabilities' eligibility and benefit amounts including a higher resource limit, a medical expense deduction, and an uncapped shelter deduction. We are not aware of research that estimates the effects of the disability-specific SNAP rules on hardship among persons with disabilities. People with disabilities are a priority category for federal housing assistance. Participants in this study described a very complex, non-transparent process for accessing housing assistance and this suggests that the targeting may not be consistent or effective across the many different agencies and housing developments managing access. The following housing search strategy 'Tip for Apply for Housing' from MassAccess, a Massachusetts resource to help people with disabilities to access housing is consistent with study participants' reported experiences (MassAccess, 2018):

> *Again, keep in mind that while applying for subsidized housing or rental assistance can be a frustrating and long process, it is important to apply at as many places at possible and get on the waiting lists at as many housing agencies and management companies as possible. The most persistent applicant will eventually get housing.*

Homeless participants reported hardships beyond material deprivation including violence, theft, and stress. Eight participants were homeless at the time of the study and even though we did not include questions about housing status in time periods prior to the study in our interviews, an additional 9 participants talked about being homeless at some point in their adult lives. The high number of participants that had experienced homelessness was not expected. It is possible that the high number was the result of our recruitment methods. Except for a single visit to a homeless shelter that resulted in the recruitment of three study participants, we did not specifically target participation among persons that were homeless or that had a history of being

homeless.[19] We are not aware of estimates of the national percentage of low-income DI beneficiaries that are homeless or have experienced being homeless. Given the adverse effects of homelessness on wellbeing, these estimates are needed.

Can the hardship associated with homelessness be lessened? The answer is beyond the scope of the study and more study is needed; however, this study did provide information. Participant's low levels of income compared to high area housing costs appeared to be at least part of the reasons for homelessness. Providing increased DI payment amounts as described above may help to prevent homelessness. In addition, a refundable federal housing tax credit targeted to low-income DI beneficiaries may also be a viable solution. The tax credit could vary geographically based on local area housing costs and beneficiaries' living arrangements.[20] Alternatively, one-time or short-term emergency assistance payments to DI beneficiaries that are at risk of eviction or homelessness may also help to prevent homelessness and the associated hardships.

Emergency shelters were important to homeless participants' wellbeing; however, participants used emergency shelters as a last resort and reported hardships associated with their shelter stays. Participants preferred alternative short-term living arrangements whenever possible, for example temporary housing for the homeless, crisis stabilization units, family/friends, recovery homes (substance use treatment), or motels. Wellbeing would be improved by increasing access to short-term living arrangements other than shelters. For example, the Massachusetts Department of Mental Health (DMH) Respite Beds program provides temporary housing and support services for DMH clients that are transitioning from one living arrangements to another. A similar program targeted to homeless DI beneficiaries would likely alleviate hardship.

Assistance to quickly transition DI beneficiaries from shelters to permanent housing would also lessen hardship. Some study participants reported receiving this type of assistance. For example, the Department of Housing and Urban Development Veterans Affairs Supportive Housing (HUD-VASH), targeted for homeless veterans, combines a rental assistance housing voucher with case management and clinical services provided by the Department of Veterans Affairs. Massachusetts has a homeless prevention program, Residential Assistance for Families in Transition (RAFT) that helps with first/last month's rent and security deposit. Also, the Massachusetts Community Support Program for People Experiencing Chronic Homelessness (CSPECH) combines Medicaid funded community support services with separately funded permanent supported housing to provide housing to individuals that are chronically homeless[21] (Byrne & Smart, 2018). While these programs were helpful to DI beneficiaries, none were specifically linked with SSA or targeted to DI beneficiaries. Comparable programs targeted for DI beneficiaries and linked with SSA, for example a multi-agency program (e.g. SSA, HUD, and Centers for Medicare and Medicaid Services) that combines rental assistance, case management

[19] If this study included people that were SSI-only recipients, the visit to the homeless shelter would have resulted in many more participants.

[20] For example, the tax credit could be limited to beneficiaries living in non-subsidized apartments.

[21] Individuals must meet the U.S. Department of Housing and Urban Development's definition of chronic homelessness. Persons must have a disability and be either continuously homeless for one year or more, or having four or more episodes of homelessness cumulatively totaling one year or more over a three year period.

and clinical services would likely facilitate and hasten the transition of homeless DI beneficiaries to permanent housing.

This study examined study participants' material wellbeing by summarizing participants' reported income, expenditures, consumption and hardships without reliance on participants' poverty status as an indicator of material wellbeing. Even so, the study data provides information on poverty measurement among DI beneficiaries. The U.S. Census bureau determines poverty status (official poverty measure) by comparing household income to thresholds that vary by family size and composition. By the official poverty measure most study participants would be considered poor or near-poor; we estimated 46 % study participants had income below the poverty threshold and 91% had income below 150% FPL. These estimated poverty levels are consistent with participants reported low consumption levels and reported material hardships.

The official poverty measure does not capture in-kind resources or informal income and this is a known limitation. Consumption-based poverty measures take these into account and therefore result in different poverty estimates compared to official poverty. The recent Council of Economic Advisor's (CEA) report noted the consumption-based estimate of poverty fell from 30% to 3% between 1961 and 2016 while the official poverty estimate fell from approximately 23% to 11% from 1961 to 1973 and cyclically fluctuated between 11% and 15% from 1974 to 2016 (Council of Economic Advisors, 2018). Based on the substantial decline in estimates of consumption-based poverty, the CEA report indicated that relative to historical standards of wellbeing, 'our War on Poverty is largely over and a success.' (Council of Economic Advisors, 2018). The low levels of consumption and the material hardships observed among participants in this study suggest that poverty remains a problem among low-income DI beneficiaries. We did find that in-kind income and informal income increased consumption relative to study participant's formal income; however, on average the increase was relatively small, approximately 43%. The increase was mainly attributed to housing subsidies and SNAP. Thus, among study participants, their formal income and their consumption provided relatively similar indications of their wellbeing.

Neither consumption-based poverty measures nor the official poverty measure account for variation in costs of living or essential expenses. The 1995 National Academy of Sciences' (NAS) Panel on Poverty and Family Assistance specified a poverty measure accounts for cost of living for basic needs, cash and in-kind resources, and necessary expenses (Citro & Michael, 1995). The NAS poverty measure has been implemented as the U.S. Census Bureaus' Supplemental Poverty Measure (SPM) and the New York City Center for Economic Opportunity (CEO) poverty measure (Blank, 2011; Levithan, 2011; Fox, 2017). Brucker et al. (2015) estimated that, among DI beneficiaries, the estimated official poverty rate was comparable to the SPM poverty rate, 29% vs. 24%. This suggests that among DI beneficiaries, the poverty rate among DI beneficiaries is high regardless of whether the official measure or the SPM measure is used.

VI. CONCLUSION

A high percentage, approximately 38% of DI beneficiaries, are living in- or near-poverty with income of less than 150% FPL (Bailey and Hemmeter, 2015). We interviewed 35 low-income DI beneficiaries to determine how they made ends meet. Except for health care consumption, we found that study participants had low levels of consumption consistent with their low levels of income. For some, the consumption levels were not adequate to meet their basis needs for food and shelter and these participants reported the hardships of being homeless, skipping meals, or having very limited food quantity or quality at the end of the month.

Policies and programs to support higher levels of consumption would improve low-income DI beneficiaries' material wellbeing and lessen or alleviate hardship. Only a small percentage of study participants reported that they were unable to work and increased employment at levels below SGA would increase beneficiaries' income. Current DI work incentives and supports focus on self-sufficiency. A focus on employment at levels below SGA to increase wellbeing may be effective. Twenty-six study participants had DI benefit amounts that were less than the FPL. Increasing these benefit amounts, for example a minimum payment equal to FPL, would increase their income. Controlling for income, persons with disabilities experience higher levels of material hardship compared to persons without disabilities (She & Livermore, 2009). Increased targeting of persons with disabilities in the eligibility determinations and benefit calculations for means tested assistance programs would support increased consumption.

Homeless participants reported hardships beyond material deprivation including violence, theft, and stress and approximately one-half of study participants reported being homeless at some time in their adult lives. Decreasing the incidence and duration of homelessness would increase wellbeing. Study participants reported receiving such help, for example temporary housing and case management services when homeless, financial assistance to pay for first/last month's rent and security deposit, and housing vouchers for persons that are homeless. While these programs were helpful to DI beneficiaries, none were specifically linked or coordinated with SSA or targeted to DI beneficiaries. Targeting of DI beneficiaries and coordination between SSA and housing agencies/programs would likely improve increase housing stability and hasten the transition from homelessness to stable housing.

The findings of this study reflect the circumstances of low-income DI beneficiaries in the Worcester, Massachusetts area. We expect that low-income beneficiaries in other areas use similar strategies to make ends meet and experience similar hardships; however, there is uncertainty. Additional studies are needed across multiple geographic areas to assess how variations in area characteristics affect how low-income beneficiaries make ends meet and their wellbeing. In addition, there is a lack of information about how persons receiving SSI based on disability make ends meet and comparable studies among SSI recipients would provide this information.

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