An End to Stigma

Challenging the Stigmatization of
Public Assistance Among Older Adults
and People with Disabilities

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National Council on Aging

About the National Council on Aging

The National Council on Aging (NCOA) is a respected national leader and trusted partner to help people aged 60+ meet the challenges of aging. Our mission is to improve the lives of millions of older adults, especially those who are struggling. Through innovative community programs and services, online help, and advocacy, NCOA is partnering with nonprofit organizations, government, and business to improve the health and economic security of 10 million older adults by 2020. Learn more at *ncoa.org* and @NCOAging.

About the Center for Benefits Access

NCOA's Center for Benefits Access helps community-based organizations find and enroll seniors and younger adults with disabilities with limited means into benefits programs for which they are eligible, so they can remain healthy, secure, and independent. The center develops and shares tools, resources, best practices, and strategies for benefits outreach and enrollment, including NCOA's free BenefitsCheckUp® online screening service. Learn more at *ncoa.org/CenterforBenefits.*

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Executive Summary

This report analyzes the origins of benefits stigma, provides examples of successful strategies used by state and local counselors to overcome benefits stigma for older adults and people with disabilities, and gives recommendations on how policymakers and program administrators can make a difference. It is based on a series of 40 interviews conducted by NCOA with state and local counselors who help older adults and people with disabilities apply for benefits, as well as a review of relevant literature.

Stigma is best understood as a negative reputation that creates real costs—emotional, social, physical, time, and financial—or the perception that costs will be incurred. These costs influence decisions about whether a particular course of action is worthwhile; in the case of benefits stigma, the clearest example of a decision affected by stigma is whether or not to apply for a public benefit. Low participation rates in benefits programs are the clearest evidence of stigma; for instance, only 41% of likely eligible people aged 60 or older were enrolled in the Supplemental Nutrition Assistance Program (SNAP) in 2013. That year alone, households with seniors and people with disabilities missed out on over $1 billion in benefits due to non-participation. The importance of public benefits programs cannot be understated, as they lifted 15.5 million seniors out of poverty in 2014.

Internal stigma arises from negative perceptions or connotations about oneself that occur when deciding to learn about, apply for, and participate in benefits programs. Shame and embarrassment about participation in the program are the most common manifestations of the internal stigma of benefits enrollment.

External stigma, on the other hand, arises from experiences or perceptions about the benefits themselves. Administrative burdens, such as long applications or difficult-to-reach social service agencies, and misconceptions about the value of a given benefit may lead eligible people to decide the reward is not worth the cost.

Counselors who educate and assist older adults and people with disabilities to apply for benefits are on the frontline in the fight to overcome stigma and encourage people to get the public assistance for which they are eligible. Interviewed counselors provided many examples of successful strategies for overcoming stigma, which fell into five main categories:

1) Challenging the narrative of "deserving" and "undeserving" poor

2) Focusing on the structure of the program

3) Correcting misconceptions about the benefit

4) Providing person-centered benefits enrollment assistance

5) Demonstrating the value of a benefit

While their efforts are valiant, counselors need support from state and federal policymakers and social service administrators in order to help a greater number of older adults and people with disabilities enroll in benefits. Agency administrators and policymakers can help by improving enrollment processes through existing waiver programs such as shorter applications, experimenting with new processes, and improving data-sharing between agencies. Policymakers also should support additional funding for counselors and social service agencies, such as Medicare State Health Insurance Assistance Programs (SHIPs), so they can continue to fulfill their vital role in the community.

I. Introduction

NCOA's Center for Benefits Access and its national partners regularly hear from field partners that the stigma low-income older adults and people with disabilities feel when applying for public benefits is one of the largest barriers to program participation.

In keeping with NCOA's mission, this report focuses on the stigma that **older adults** and **people with disabilities** encounter when applying for benefits. However, many of the findings may be broadly applicable to anyone applying for public assistance programs, as benefits stigma is not a phenomenon limited to seniors or people with disabilities.[1] Throughout this report, the terms "benefits," "welfare," and "public assistance" are used interchangeably to designate public programs that provide a measure of well-being and support by distributing social income. Notably, this includes programs traditionally designated as "social insurance."

Stigma is best understood as a bad reputation or taboo. If something is stigmatized, it is surrounded by negative perceptions and connotations. As a result, stigma creates costs—emotional, social, physical, time, and financial—that influence decisions about whether a particular course of action is worth undertaking. In the case of benefits stigma, the clearest example of a decision affected by stigma is whether or not to apply for a benefit; stigma also affects the political will to defend, expand, or cut certain programs.

Evidence of stigma shows up in low participation rates for certain programs. For instance, only 41% of people aged 60 and older who are likely eligible for the Supplemental Nutrition Assistance Program (SNAP) in 2013 were enrolled in the program.[2] About one-third of people likely eligible for Supplemental Security Income are not enrolled in the program.[3]

The key to fighting the stigma around benefits is recognizing that **no one should be economically insecure.** Public benefits programs are a key to making this vision a reality. In 2014, benefits programs kept 15.5 million seniors out of poverty, cutting the elderly poverty rate from 43.7% to 10%.[4] Social Security alone kept 22 million people out of poverty (including 1.1 million children and 6.2 million adults under age 65) in 2013. SNAP reduces poverty by 14-16% and extreme poverty by half.[5]

Counselors who help people apply for benefits programs are on the frontline of the fight to overcome this stigma and help people enroll in these programs. All counselors, as experts in benefits enrollment assistance, intuitively develop techniques to help their clients feel more comfortable about applying for benefits, some of which are more or less successful than others. While counselors fight this battle against stigma one-on-one, policymakers, agency administrators, and the public should support them.

NCOA's Center for Benefits Access hopes this report is useful for everyone who wants a future where people who need public assistance no longer feel shame or embarrassment about applying for benefits, and where benefits and the agencies that administer them are responsive to these individuals' needs.

Methodology

NCOA conducted in-depth, semi-structured phone interviews between August and October 2015 with benefits counselors who work primarily or entirely with Medicare beneficiaries. (Interview questions can be found in Appendix B.) Some interviews were with a single counselor, while others were conducted with multiple counselors who work in the same agency. In all, 40 counselors were interviewed. Each counselor helps older adults and/or people with disabilities apply for benefits for which they are eligible.

While these counselors serve many different geographies and populations, counselors were self-selected through a convenience sample and should not be considered a representative cross-section of this profession across the United States. The states of Wisconsin, New York, and Virginia were oversampled. Half of the counselors worked primarily in rural communities, while the other half work in suburban or urban communities.

All counselors worked at community-based organizations, most in the traditional aging network, i.e., at State Health Insurance Assistance Programs (SHIPs), Area Agencies on Aging (AAAs), and Aging and Disability Resource Centers (ADRCs). Others worked in senior housing, health care, or legal aid.

When the report refers to a counselor, these are the people being quoted or paraphrased. These professionals, who help many low-income older adults and people with disabilities every day, are the true experts on access to benefits, with well over a century of combined experience in the field. NCOA is aggregating and providing a theoretical backdrop for their insights.

Additional information that informed this report was gleaned from NCOA's 15 years of working to improve access to benefits and the Center for Benefits Access' six years of experience as the resource center for the Medicare Improvement for Patients and Providers Act (MIPPA), providing technical assistance and funding to the aging network and other community-based organizations across the country that help people enroll in benefits.

II. Sources of Stigma

The first step in overcoming stigma is understanding its origins. A review of the academic literature on stigma as a psychological phenomenon in general, and benefits stigma more particularly, finds that negative associations spring primarily from two sources, internal and external.[6]

- **Internal stigma** is directed *internally*, i.e., toward oneself. This may be personal shame or blame, such as frustration that the client feels they cannot care for themselves, or feelings of embarrassment that a friend, relative, or someone else will judge a client for relying on a benefit.

- **External stigma** is directed *externally*, i.e., toward the benefit or an agency that administers the benefit. It is a result of real or perceived negative experiences around the benefit or agency.

The Center for Benefits Access designates five common federal/state benefits program as core benefits: the Supplemental Nutrition Assistance Program (SNAP, formerly the Food Stamp Program); Medicare Savings Programs; the Medicare

Prescription Drug Part D Low-Income Subsidy (Extra Help); Medicaid; and the Low-Income Home Energy Assistance Program (LIHEAP). These benefits and their federal eligibility requirements are discussed in more detail in Appendix A.

Counselors were asked how often clients were hesitant to apply for each core benefit due to stigma. They were also asked about the existence of stigma around other common benefits and social insurance programs such as Social Security, Medicare, Supplemental Security Income, and Veterans' benefits.

Of these, the vast majority of interviewed counselors noted that they encountered resistance due to stigma from older adults for only two of the benefits: SNAP and Medicaid. In fact, when asked a general question about their experiences with benefits stigma, many counselors began the interview by talking about SNAP without prompting, having assumed the interviewer was asking about this benefit specifically. This suggests that for many, even those who work professionally in the field, "welfare," "SNAP," and "food stamps" are synonymous.

Sources of stigma are interrelated and are not mutually exclusive. The factors that create benefits stigma are experienced by most people, but affect each individual in different ways. Some general characteristics that change the way people perceive stigma are presented below.

Characteristics affecting the perception of stigma

Age

Many counselors reported that resistance is much greater among older adults who belong to the generation born during the Great Depression, who are now in their 80s and 90s. One counselor said that they are more likely to consider their need for benefits to be a personal failing and are embarrassed to admit they need help. Counselors noted that those in their 60s or 70s are less likely to voice negative feelings about the benefits.

Disability status

Counselors who worked with a population of younger Medicare beneficiaries who qualified based on disability status noted that this population is less likely to be affected by stigma. A counselor in New York State suggested that this is because these individuals have already completed the process to enroll in Social Security Disability Insurance and Medicare, which is long and onerous. "By the time they're talking to a counselor, only about 10% need more discussion before they start applying for benefits," noted one counselor in Wisconsin. She speculated this was due to the suddenness of disability, compared to retirement, and added that younger people with disabilities who have been on Social Security for a long time are less likely to feel stigmatized than older people with more recent disability status who thought they would be able to work until they retired.

Racial biases

Several counselors noted potential applicants' tendency toward racialized language in their interactions. This tendency is well-evidenced in research. Studies by Bas van Doorn and Shanto Iyengar, among others, have thoroughly demonstrated the unconscious association of false stereotypes about people of color, and more specifically African Americans, with certain public benefits. This is despite the fact that the majority of recipients of most means-tested and universal programs are white.[7] Such unconscious biases are shared—though not interpreted in the same way— by all Americans; they form a part of a vocabulary handed down from the past that is reproduced by people as they use it to navigate their social and economic terrain.[8]

Immigration status

Counselors who work with eligible older adults who immigrated to the U.S. later in life also reported mixed views on benefits among this population. One common thread was reduced *internal* stigma—these immigrants did not feel the same cultural sense of shame in accepting public assistance as those who had lived in the United States their whole lives. However, counselors—especially those working with Latino populations—noted that many such immigrants were nevertheless reluctant to apply for benefits because they have low trust in public social services. According to counselors, many non-citizen residents worry benefits applications will affect their immigration status.

Residence

Counselors noted that a client's location is relevant to their feelings of stigmatization. For instance, a counselor in the Chicago area mentioned that people living in suburbs with higher median incomes tended to say they would be "taking benefits away from others" more often than those who lived in lower-income areas. Counselors in Maryland and Philadelphia agreed that those in lower-income communities were less likely to feel stigmatized by their community, as many of these people were "chronically low-income" and had already been relying on public assistance for a significant portion of their lives. Most counselors agreed that people who live in a dense area with high penetration of social services and benefits are less likely to feel isolated and embarrassed as a result of benefits enrollment. One counselor in Massachusetts said that people who live in senior housing regularly see their neighbors use benefits, and this makes it seem more acceptable.

On the other hand, a counselor in Kentucky noted people in the urban areas in which she worked are more likely to be resistant to apply because many of them had good jobs in the past and were not accustomed to needing benefits. This suggests that benefits stigma is less of a problem in regions with chronic poverty combined with an already high percentage of benefits enrollment (often correlated with strong social services) than it is in regions where this experience is less commonplace. However, this does not necessarily neatly map onto an urban-rural divide.

How to identify sources of stigma

Below are quotes from clients, as reported by counselors. Counselors can more effectively counter stigma if they can identify the source based on what a client says or implies.

Internal stigma

- "I don't want to be one of those people with the card." [EBT cards]
- "Other people need these benefits more than me."
- "I was always taught you live with what you've got."
- "My neighbor could find out I'm getting food assistance or fuel help."
- "Welfare isn't for me, it's for young moms who pop out kids."
- "I don't need any handouts."

External stigma

- "They're going to take my house away." [fear of estate recovery]
- "It's not worth the time to only get $15." [SNAP minimum benefit]
- "I don't trust the quality of care because it's on a budget." [Medicaid]
- "I don't want to deal with the social services department."

A. Internal Stigma

Internal stigma arises from negative perceptions or connotations about oneself that occur when deciding to learn about, apply for, and participate in benefits programs. As counselors noted, shame and embarrassment about one's poverty or participation in the program are the most common manifestations of the internal stigma of benefits enrollment. In other words, internal stigma primarily creates emotional and social costs for the potential applicant. Obstacles that create and exacerbate this aspect of stigmatization are discussed below.

Program structure

Programs structured as universal benefits or "social insurance" such as Social Security and Medicare are substantially less stigmatized than means-tested benefits such as SNAP or Medicaid. None of the counselors interviewed had ever heard of stigma involving Social Security retirement benefits or Medicare. This falls in line with surveys from the National Academy of Social Insurance that show a supermajority of Americans, cutting across all political affiliations, would like to not only maintain but expand Social Security and would be willing to pay more in taxes in order to do so.[9]

In addition, there is little stigmatization of programs structured *around* Social Security and Medicare. For example, a counselor from Virginia said that the involvement of the Social Security Administration in enrolling in Part D Extra Help was an important part of why there is little resistance to applying for that particular benefit.

Method of receipt

The method of receipt of benefits can affect perceptions and stigma. Medicare Savings Program benefits appear to be a normal part of Medicare and Social Security. The Part B premium is normally taken out of a Social Security check each month; for Medicare Savings Program recipients, it is added

back in. Coverage of cost-sharing happens at the backend, and many recipients may not even be aware it is occurring. As a counselor in Georgia noted, "Most people think Medicare Savings Programs and Extra Help are just part of Medicare." Similarly, LIHEAP goes directly from the state to the utility provider.

Many counselors noted that clients are afraid of being marked as a SNAP recipient due to the electronic benefits transfer (EBT) card. Though the EBT card looks like a regular debit card, some counselors speculated that many seniors still picture the very conspicuous food stamps, or else do not have or know how to use a debit or credit card. One counselor in Wisconsin said that the switch from food stamps to the EBT card has been extremely successful in reducing stigma. On the other hand, a Kentucky counselor told the story of a client whom she had seen on the day of the interview who specifically said she did not want to be "one of those people with the card."

Qualification

Methods of qualification also change perceptions of programs. A counselor in New York State said that many people "think Extra Help is something everyone automatically gets due to the auto-qualification" from qualifying for Medicare Savings Programs.
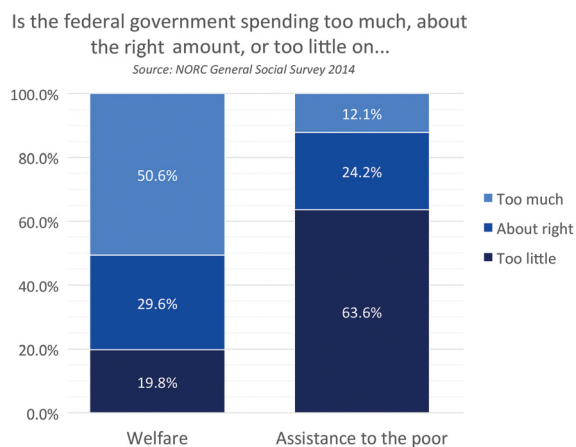
Use of language

In general, the word "welfare" has become extremely stigmatized, as the results from the nationally representative 2014 General Social Survey shown in Figure 1 demonstrate. Many conflate the stigmatization of the word "welfare" with unpopularity of the *concept* of welfare, but Figure 1 shows that it is the term rather than the concept that contains the stigma.[10] When asked if people thought the federal government spends too much, too little, or about the right amount

on "welfare," 50.6% said "too much." However, when asked the same question, but with "welfare" replaced by "assistance to the poor"—the same concept with a different name—63.6% said the federal government spends "too little."

The majority of Americans, in other words, support the concept of and greater spending for welfare, but dislike the term "welfare." More specific and local versions of this phenomenon were reported by many counselors.

Figure 1: "Welfare" vs. "Assistance to the poor"

Is the federal government spending too much, about the right amount, or too little on...
Source: NORC General Social Survey 2014

	Welfare	Assistance to the poor
Too much	50.6%	12.1%
About right	29.6%	24.2%
Too little	19.8%	63.6%

One counselor noted that stigma around SNAP has decreased "substantially" since the name officially changed from the Food Stamp Program to SNAP. Wisconsin and California have state-specific names for their programs (FoodShare and CalFresh, respectively), and counselors in these states suggested that these names carry less stigma than SNAP or food stamps. This is not a result of *inherent* stigma in the name SNAP or food stamps, but rather because these names lack the stigma that has become associated with the program's official name.

Counselors noted that the name Medicaid involves less, but still some, stigma. For instance, a counselor in New York noted that people became hesitant to apply for Medicare Savings Programs only when they learned that they are run by the state Medicaid agency. A counselor in northern Virginia concurred, stating that resistance increases only when the word "Medicaid" is mentioned.

On the other hand, a counselor from Georgia claimed, "Most senior clients don't know the difference between Medicare and Medicaid." Another counselor from New York State said most people "consider Medicaid something that young people use," and applicants generally do not consider Medicare Savings Programs part of Medicaid.

Perceptions of merit

A counselor in Missouri said that she regularly encounters clients who come to her "crying because they're embarrassed that they can't take care of themselves." Many other counselors reported that clients refused to apply for SNAP or Medicaid at first because "others needed it more than they did," indicating that they consider people who need the benefit to be in a qualitatively different category than themselves. Less altruistic-sounding variations are complaints about "the other people who take advantage of the system," a common refrain heard by counselors across the country.

This moral evaluation by potential applicants of those in need, or a certain segment thereof, was mentioned by many counselors. One counselor in California characterized the idea that some people are more deserving of benefits than others as "brainwashing" people in need. Many applicants consider accepting these programs to be owning up to a personal failure, leading to deep—but in the context, wholly understandable—feelings of shame and embarrassment about their poverty and need for assistance from the public.

B. External Stigma

External stigma arises from negative perceptions and connotations of the benefits themselves. For public assistance programs, external stigma often manifests itself in costs associated with administrative burdens. These burdens are the costs that people incur when learning about, applying for, and participating in a benefit as a result of barriers preventing access. In other words, applicants must decide if the amount of time, money, and emotional, mental, and physical energy that must be expended in order to overcome these barriers is worth it to them.[11]

Application process

Several counselors noted that a substantial portion of their senior clients have never been enrolled in means-tested programs, and therefore the application process comes as a surprise. To illustrate the differences between programs, a counselor in western Virginia contrasted the applications for Medicare Savings Programs and Extra Help.

She explained that the latter was "cut and dry" and "short and sweet" and takes only about five minutes to complete. On the other hand, the application for Medicare Savings Programs is "long and drawn out" and "invasive, requiring lots of documentation." She noted that it could take up to 30 minutes even with the help of a trained counselor. A counselor in Maryland suggested that "borderline" clients—that is, those whose income or assets are near eligibility thresholds—are the most likely to consider applications not worth the time.

Several counselors noted that many people are reluctant to give out information for privacy reasons. A California-based counselor said she has a hard time getting people to be forthcoming about their income.

In many states, SNAP applications themselves are quite long, often because they are combined with applications for other benefit programs. For instance, the Alaska SNAP application is 24 pages, with no online application option.[12] In Texas, the combined paper application for SNAP, Medicaid, and TANF is 31 pages.[13] By contrast, Alabama has instituted an Elderly Simplified Application waiver from the USDA. As a result of this waiver, the SNAP paper application for older adults and people with disabilities is just two pages.[14]

In some cases, the post-application processes for applying for SNAP are drawn out or difficult. Any part of the application process that requires an in-person interview or any other such hurdle may represent a unique impediment for older adults and people with disabilities. As a counselor from Massachusetts noted, in-person interviews are a significant barrier for SNAP enrollment in that state because of the logistical difficulties in getting to interview sites.

Concerns about estate recovery and states placing liens on homes affects applicants' willingness to apply, as well. This can be a legitimate concern for families applying for Medicaid coverage for long-term services and supports. However, several counselors noted a similar concern and stigma related to Medicare Savings Programs because applications in some states still contain questions pertaining to estate recovery, despite the fact that Medicare Savings Programs beneficiaries have been exempt from estate recovery for Medicaid cost-sharing since January 2010. Though these questions now have no meaning, according to counselors in Wisconsin and Massachusetts, they remain on the application forms and make clients understandably leery about applying for this benefit.

Some clients, one Virginia counselor noted, also are afraid of being somehow "penalized" by state agencies if they complete an application but are ultimately denied the benefit. Though an unfounded fear, absent education from counselors, such a belief may dissuade potential applicants.

Administering agency

People rely on their experiences to make judgements, and some people have had negative experiences with social service agencies in the past. The reason for this can be as simple as having dealt with a less-than-friendly public servant, having been denied benefits previously, or systemic issues like extremely long processing times or difficult-to-read and/or incomplete notices.

For instance, one counselor said clients will "do anything to avoid the social services department." Counselors in another state agreed that many people had negative experiences with their state agency and did not want to apply as a result, saying that the agency administering benefits programs treats people like "second-class citizens" and forces them to deal with long wait times. These counselors described people who would "go without food and money to avoid dealing with [the agency]." A counselor in a third state said there is "lots of stigma around benefits from the [agency]" itself, and that workers in the agency are "often confused" by the "alphabet soup" of benefits.

More and more states are moving benefits applications and appeals online. While in some states this has led to increased efficiency, in others it has led to new problems that may negatively affect individuals' willingness to apply for benefits, at least in the short-term as the platform is rolled out. A counselor in one state said that many of her clients had simply given up on applying or being re-determined for SNAP because of huge wait times in the customer service system. In several cases, counselors said the digitalization of applications had broken the lines of communication between them and the agency by forcing all calls, even from counselors, into a single toll-free number with long wait times.

On the other hand, an online system done well can improve efficiency and make people more likely to apply. A counselor in Washington said they are able to enter the state's benefits system and track application processing, and even flag applications as urgent, so determinations can be made immediately. States implementing robust online systems like Washington's are likely to see large improvements in access in the long-term.

Value of benefits

One of the most common reasons not to apply for SNAP that counselors hear is that applicants assume they will receive only $15, the minimum monthly benefit for households with a member who is aged 60 or older or who has a disability. In 2013, the median monthly benefit for a senior household was $129, and only about 14.4% of all SNAP households with a senior received the minimum benefit.[15] However, applicants and counselors alike share a misperception that receiving the minimum benefit is much more common than analysis of the program's data demonstrates. One possible source of this is selection bias. The minority who receive the minimum benefit are more likely to air their grievances about the benefit size, thereby skewing public perception of benefit amounts.

Regardless, there is a perception that it is not worth the time and effort required to apply for SNAP. After all, filling out an application, gathering documentation, and scheduling and completing an interview can be very arduous, especially for people with mobility or cognitive difficulties caused by age or disability. When combined with other sources of stigma, this may tip the scales for people who were already on the fence about applying.

Despite the issues of benefit size, it is notable that in 2014, take-up of the Excess Medical Expense Deduction, which allows most seniors and people with disabilities to deduct out-of-pocket medical expenses in excess of $35 from their monthly income for SNAP eligibility and benefits determinations, was just 7.5% for applicable

beneficiaries aged 60 and over and 10.2% for beneficiaries with disabilities who were eligible for the deduction.[16] Yet a Kaiser Family Foundation report found that the average Medicare beneficiary spent $4,734 out-of-pocket for health care in 2010. Thus, the low take-up rate has little to do with a lack of deductible expenses.[17]

Why do so few people use the deduction? One possibility is insufficient instruction or information provided by the administering agency; in other words, an administrative burden. For example, the Texas SNAP application has an applicant check if they have out-of-pocket medical expenses but provides no further information on how to

Figure 2: Declaring Deductions on the Texas SNAP Application

document this or what it means. Compare Section P (a question to determine the Dependent Care Expense Deduction) to Section Q (which determines the Medical Expense Deduction) in Figure 2, taken from the state SNAP application.[18] Unlike Section P, Section Q provides no space to claim an amount of medical expenses; clients are expected to bring documentation to interviews but are given vague documentation requirements in the instructions on page 3 of 31 ("Bills, receipts, or statements from health-care providers … These items should show costs you have now and costs you expect in the future"). Nor are they told what entails a claimable expense or why they should submit documentation of medical expenses.

Programmatic burdens are not restricted to SNAP. A counselor in California noted stigma related to Medicaid, explaining that many people do not want to apply for Medicaid because they "don't trust the quality of care because it's on a budget" or because they "do not want to lose their doctor." Both of these factors that contribute to stigma are *legitimate* concerns for applicants that can only truly be corrected through changes to the program.

Counselors in New York City and Wisconsin said that people living in public or subsidized housing are often wary of applying for programs that affect their out-of-pocket medical costs. Because housing authorities use medical expenses such as Medicare Part B premiums and other cost-sharing as an income deduction, applicants worry that benefits like Medicare Savings Programs will cause their rent to go up, resulting in a net loss to disposable income. While this is unlikely due to the way rent in public housing is calculated, to reach this conclusion requires applicants to perform complicated and technical cost-benefit analyses, which are time-consuming and prone to mistakes, and understandably outside the realm of expertise of most people.

III. Overcoming Stigma

Stigma is not an inherent condition; it can be overcome, and benefits counselors, caseworkers, program administrators, and policymakers all have a role to play. Throughout the interviews, counselors shared how they help people overcome this stigma on a daily basis. Additionally, the interviews demonstrated how important policy is at the local, state, and federal level in both creating and dispelling stigma.

A. Recommendations for Counselors

When people come to a benefits counselor looking for help, many are only vaguely aware of the options available to them. This is especially true of older adults and people with disabilities, who may be looking into applying for public assistance for the first time after moving from employment to a fixed income due to retirement or an inability to work.

Counselors noted several successful strategies for overcoming stigmatization of benefits when talking to clients, which are presented in more detail below.

Countering internal stigma

Counselors identified three main strategies for overcoming individuals' shame and embarrassment that they need public assistance:

1) **Challenging the narrative of "deserving" and "undeserving" poor**

2) **Focusing on the structure of the program**

3) **Correcting misconceptions about the benefit**

Challenging the narrative of "deserving" and "undeserving" poor

Most counselors interviewed said the strategy they used most commonly and successfully is to dispel notions that a person is "accepting a handout," which is the source of a great deal of shame and embarrassment. Rather, many point to Social Security and Medicare—near-universal social insurance benefits that are extremely popular and free of stigma—and point out that, in reality, clients "earned" these benefits in the same way. Taxes fund all benefits programs, and most clients have been paying taxes their entire working lives. One California counselor said she frames the benefits as "rights." A counselor in New York State said this method works on "about 95% of people" who are reluctant to apply.

One of the more unique methods of countering stigma in this way comes from a counselor in East Texas, who tells reluctant clients, "I'm waiting on my 'welfare' from the government every month—my retirement check from the Air Force." According to this counselor, showing that she has no shame accepting benefits from the government and drawing parallels between paying taxes while working to pay for these benefits to receiving a pension from the government, helps people become more likely to complete an application.

While this may not work for every counselor or client, similar appeals could be made using Social Security or Medicare. Indeed, two counselors said that calling programs "Medicaid from Social Security" or "Extra Help from Social Security" made people substantially more likely to apply for a benefit.

Focusing on the structure of the program

When meeting with clients from higher socioeconomic areas in the Chicago suburbs, one counselor explains to older adults that programs like SNAP have "special rules for people your age because … cost of living goes up but your income does not." Unique among those interviewed, this particular counselor said that this language is substantially better than the "you worked for it" pitch, especially with clients who say that "someone else needs it more."

This counselor said that the most powerful strategy is simply to tell people that "we were just in your area and a lot of people were eligible," which makes applicants feel less like it is an individual failing. A counselor in Connecticut "breaks out stats" to show how many people receive SNAP in a neighborhood, demonstrating to clients that they are not alone in needing the benefit and overcoming the way that poverty is hidden in many communities.[19]

Similarly, a counselor in western Massachusetts said she talks about how the current Social Security benefit is lower than it used to be. Other counselors discuss the economy and issues related to debt and expenses that older adults and people with disabilities face. This helps people understand that it is a structural failing that people need to rely on benefits in their old age, rather than a personal issue.

A counselor in Texas said the best way to get people on benefits is to use another benefit as a gateway. Her recommendation, which was shared with other counselors, was Extra Help. Many counselors said that a great deal of their clients come looking specifically for help with their Part D prescription drug benefit, as medicine is expensive and becomes a much larger part of budgets as people get older.

This expense is an important talking point for several counselors and can help them convince people to enroll in other benefits, such as SNAP, which can serve to relieve the burden on other parts of someone's budget. As one counselor explained, "people tend to compartmentalize help," so describing the less-than-obvious ways

certain benefits such as SNAP or LIHEAP can free up money for expensive medicine or health care expenses, for instance, is a way to decrease the consternation people feel about these benefits in particular.

Correcting misconceptions about the benefit

Several counselors from different areas of the country said that educating people on benefits and correcting their misconceptions are the most important means to overcoming shame and embarrassment. A counselor from upstate New York and another from southern California said they provide detailed information or presentations on the history and intention of each benefits program, and "people respond to it," according to the counselor from New York. This is especially useful for Medicaid, which consists of a number of different programs that many people may not know about.

When people worry about being seen with an EBT card, a Kentucky counselor shows an EBT card and a debit card issued by a well-known bank, both of which feature an American flag motif, and points out to clients that no one will know they are using an EBT card unless they tell them.

Several counselors who serve agricultural areas in rural Wisconsin said they have had a great deal of success encouraging people to apply for SNAP by explaining that it "helps local farmers" and "it's administered by the US Department of Agriculture and not by Health and Human Services."

For Medicare Savings Programs, several counselors noted that they can encourage people to apply simply by describing the structure of the program. One counselor tells people that Medicare Savings Programs "give you your money back," which is reflected as a line item in their Social Security check.

Countering external stigma

Counselors identified two main strategies for overcoming the stigma that results from experiences or perceptions about the benefits themselves, or the processes of applying for them.

1) **Providing person-centered benefits enrollment assistance**

2) **Demonstrating the value of a benefit**

Providing person-centered benefits enrollment assistance

A 2012 randomized field experiment found that low-income individuals who received assistance completing the Free Application for Federal Student Aid (FAFSA) for themselves or their children were substantially more likely to submit their FAFSA than the control group, who received only information about financial aid but no assistance. This one-on-one assistance was ultimately associated with a higher likelihood of not only completing the FAFSA form, but also receipt of financial aid and university attendance.[20]

As both the researchers and many counselors noted, the same concept demonstrated in the study applies to applications for benefits. A counselor from rural upstate New York said that, in her experience, providing application assistance in an applicant's home is especially effective, as there is reduced risk of them forgetting documentation, and people feel comfortable in a safe space. The counselor explained that the biggest problem in her service area is transportation, and home-based application assistance does not risk a client missing an appointment because they cannot find transportation.

A counselor in Texas often sees applicants who are concerned about the time and length of applications. She tells them, "It's no extra work for you, just for me. I'll send in the application and if you don't want it, don't use it." For people who are intimidated by

the length and complexity of applications, this sort of reassurance can be very helpful. It also cuts down on the need for return visits, which are a burden to both client and counselor.

Providing help within community-based organizations can help those who do not want to deal with the social services agency or multiple agencies. As one New York State counselor said, people "don't want to deal with the drudgery of this agency, that agency." A Virginia-based counselor said that being co-located with the local Area Agency on Aging decreases stigma because people knew they are coming to get help. One counselor who works at an NCOA Benefits Enrollment Center in California said the Benefits Enrollment Center branding is very helpful, as it makes it clear that they are able to screen for and assist with applications for all benefits.

What is person-centered assistance?

NCOA's Center for Benefits Access encourages organizations to practice the principle of **person-centered assistance** when helping people apply for benefits. Rather than focusing on a specific benefit, clients are screened for **all** benefits available (for example, with NCOA's free online screening tool, BenefitsCheckUp®), and application assistance is provided for any benefits for which they screen eligible. This reduces the burden on both counselors and clients, as they only need one session to screen for benefits. Most importantly, it allows counselors to show the effects of benefits enrollment in a holistic manner, rather than focusing on compartmentalized help for items such as drugs or groceries.

Demonstrating the value of a benefit

A counselor in California described how she goes through a client's budget, explaining what assistance from benefits could help them afford, such as buying clothes, paying their credit card bill, or having a nice meal. This is especially helpful to show how savings from a benefit in one area, such as in food from SNAP or Medicare premiums from a Medicare Savings Program, can have cascading positive effects across a person's entire budget.

A counselor in Wisconsin said she asks clients who are reluctant to apply for SNAP because they don't think a small benefit is worth it: "If you saw $15 lying on the ground, would you take it?" This counselor frames SNAP as a "grocery store coupon." Some counselors give an example of what $15 can buy—or even show them physically, with an example grocery bag filled with $15 worth of food.

Additionally, applying for one benefit can be an entry point for other benefits. Several counselors in states where SNAP recipients are automatically eligible for the Lifeline free cellular phone program said that people are willing to sign up for SNAP to get the Lifeline phone. Similarly, the "heat-and-eat" option—in which receipt of LIHEAP increases SNAP benefits—is an incentive for people to apply for both programs. Though Congress narrowed this option in the 2014 Farm Bill, requiring a higher threshold of state investment, 12 states have increased their commitment of funds in order to maintain the option.[21]

B. Recommendations for Administrators and Policymakers

Benefits counselors are not the only group who have to avoid and reduce benefits stigma. Program administrators and policymakers at the state and federal level can pursue changes that suppress external stigma by making it easier for people to access benefits and have more positive interactions

with their state and local administrative agencies. They can also challenge the dominant narratives that lead to internal stigma.

Improving enrollment processes

There are many techniques to streamline enrollment processes and reduce administrative burden, which are not used evenly or regularly in the United States. Policy options to streamline enrollment processes and reduce administrative burden in order to improve benefits access include:

☑ **Existing waiver programs.** States already have a number of options to improve their benefits enrollment processes. For instance, states can implement an Elderly Simplified Application Project (ESAP) for SNAP, which is a package of reforms, including a shortened application, removal of in-person interview requirements, and lengthened re-determination periods. Six states have implemented an ESAP at the time of writing. In addition, states can implement telephonic signatures to avoid the lengthy mail exchange required for ink signatures.[22] For Medicare Savings Programs, states have the option to remove asset tests, change income levels, and improve re-determination processes. See NCOA's publication *State Options to Streamline Eligibility for Medicare Savings Programs* for more information.[23]

☑ **Improved data-sharing.** Requiring applicants to list and verify their own income and assets is a burdensome practice for both applicants and administrators. Improved data-sharing between federal and state agencies can avoid this, as the federal government already has income data in two silos—the Internal Revenue Service and Social Security Administration. The Marketplace Data Services Hub created for the Affordable Care Act provides a template for this sort of data-sharing with administering agencies. In addition, an Urban Institute study found that combining prior-year income data and current-year new hires or wage data is enough to determine eligibility for between 50% and 79% of all people who are eligible for Medicaid.[24]

☑ **Experiment with new processes.** One possibility for an entirely new enrollment process is using state or federal tax returns to *automatically* enroll people in benefits, which would circumvent the issues of stigma. Tax returns contain all relevant income data, and previous year income and employment data can predict eligibility for a substantial percentage of the potentially eligible. For programs that continue to have asset tests, reported returns to capital (such as capital gains, dividends, and interest) could be used instead. Don Moynihan, a scholar of public management at the University of Wisconsin, has called auto-enrollment "the most dramatic way to reduce burden for applicants."[25] In the BadgerCare Medicaid program in Wisconsin, for instance, a one-time auto-enrollment using state data enrolled many individuals who were eligible but not enrolled.[26] Another possibility is a single, federal online portal similar to the Marketplace, where applications for benefits can be accessed. This could be done through the currently existing My Social Security webpage.

Additionally, some advocates suggest abrogating interviews for programs that require them, such as SNAP. However, this policy has seen mixed results, and can decrease the satisfaction of applicants and negatively impact timeliness of determinations.[27] As long as the interviews are accessible (for instance, by making

interviews via phone or internet an option), USDA should provide a standard protocol for case managers, directing them to use the interviews as an opportunity to both maximize the size of their clients' benefits through deductions and educate clients on how to use their benefits if approved.

Supporting State Health Insurance Assistance Programs (SHIPs)

SHIP counselors are funded by the US Administration for Community Living to help Medicare beneficiaries make decisions about their health benefits. In 2015, SHIPs provided one-on-one assistance to 3.5 million people, over a third of whom had incomes below 150% of the federal poverty threshold. SHIP funding has not kept pace with the 10,000 people who age into Medicare daily, and has even been threatened with funding cuts. In order to maintain this network and the invaluable one-on-one counseling, policymakers should support increased funding to keep step with inflation and the growing number of Medicare beneficiaries.

IV. Conclusion

The stigma around public benefits programs is multifaceted, and overcoming it will require concerted effort from antipoverty advocates at the local level and in state and federal agencies and legislatures. But it can be done.

Benefits stigma does not have to be permanent. Counselors, administrators, policymakers, and the public can change perceptions of poverty as an individual failing and something to be ashamed of, and in so doing overcome negative connotations of welfare policies, whether directed toward the benefit or the people in need. This will lead to getting older adults into benefits programs that can have significant impacts on their health and economic security.

In addition to being very effective programs that lift people out of poverty, many benefits, such as Medicare and Social Security, are extremely popular. Research shows that a majority of Americans *want* the government to spend more on assistance for the poor. A report from the National Academy of Social Insurance found that a majority of Americans of all generations and political leanings are willing to pay more in order to help others, as well as to increase the minimum benefit to low-wage workers through Social Security.[28]

Counselors, who help individuals each day, can change perceptions about benefits that people otherwise may be ashamed to accept. Policymakers can pass laws and change systems that tear down barriers that keep people from accessing these programs.

One of the common refrains heard from counselors was that many older applicants are heartbroken because they never imagined they would need to rely on government assistance just to meet their daily needs. Every day—through no fault of their own—millions of older Americans have to choose whether to pay out-of-pocket for medications, food, housing, or utilities. They live just one bad break, one accident, or one paycheck away from economic disaster. No one can ever be fully sure that they will not wake up on any given morning and find themselves in or near poverty.

Our system of benefits programs is the safety net that exists to, if not fully remove this possibility, at least cushion the fall. It will be even more effective if we can remove the barriers identified in this report, by the counselors who work daily with those in need and know the safety net best. If we can work together to end the stigma that permeates our system of public assistance, it will be a major step forward in reducing, and eventually eliminating, poverty for seniors and people of all ages in the United States.

Appendices

Appendix A: Core Benefits

NCOA's Center for Benefits Access classifies five common means-tested benefits as "core" for older adults and adults with disabilities. (Eligibility levels listed are federal, and income does not include deductions. Asset levels are for 2016. State-administered benefits may have more generous eligibility guidelines in some states.)

☑ **Medicare Savings Programs (MSPs)** help pay Medicare Part B premiums, and possibly other costs in Original Medicare depending on income level. *Eligibility: Income below 135% of the federal poverty level (FPL); countable assets below $7,280 for an individual, $10,930 for a couple.*

☑ **Part D Extra Help/Low-Income Subsidy (LIS)** helps pay costs for the Medicare Part D prescription drug benefit, with sliding scale based on income and asset level. *Eligibility: Income below 150% FPL; countable assets below $13,640 for an individual, $27,250 for a couple.*

☑ **Supplemental Nutrition Assistance Program (SNAP),** formerly the Food Stamp Program, provides financial assistance each month for groceries. Benefits are transferred onto an EBT card. *Eligibility: Income below 130% FPL; countable assets below $3,250 for a household with an elderly or disabled member.*

☑ **Medicaid** helps pay various medical costs, including some not covered by Medicare. *Eligibility: Depends on state and program; many states set income level at 75% FPL, others at 100% FPL; most states limit assets to $2,000 for individual or $3,000 for a couple.*

☑ **Low-Income Home Energy Assistance Program (LIHEAP)** helps pay energy, heating, and cooling costs with direct payments to the utility company. *Eligibility: Income below 150% FPL.*

Other benefits that NCOA partners help people apply for include Supplemental Security Income (SSI); Temporary Assistance for Needy Families (TANF) and Women, Infants, and Children (WIC) for older adults responsible for children; property tax relief; public housing; State Pharmaceutical Assistance Programs (SPAPs); and many other state and local programs.

Appendix B: Interview Questions

All questions below were asked in some manner during each interview. However, specific questions often required more probing. After the fifth and sixth questions, the interview structure usually became much more free-flowing, as counselors talked about their specific experiences with applicants and stigmatization of benefits.

Hello, [name.] I am [name] with the National Council on Aging's Center for Benefits Access. We are currently interviewing counselors who help low-income older adults and people with disabilities apply for public benefits in order to uncover strategies counselors use to overcome resistance due to stigma. We define stigma as feelings of embarrassment or shame that people feel when they need to rely on public benefits to make ends meet. Stigma can come from personal shame or embarrassment that others, such as friends, family, or neighbors, may find out that a person needs assistance.

This interview consists of 13 questions and should take no longer than 30 minutes. Information you provide in this interview will be used solely for the purposes of this study. This interview is being recorded.

Q1: Do you consider the population you serve to be mostly urban, suburban, or rural?

Q2: Please describe the demographics of your typical clients. What's the typical age, gender, disability status, racial and ethnic identity of your clients?

Q3: Please describe the economic circumstances of your typical clients.

Q4: Do you generally provide application assistance in-person, over the phone, or through some other medium?

Q5: How often do you encounter clients who [come to your office/call you] but are hesitant to apply for benefits, particularly because they feel stigmatized?

Q6: What strategies do you find most successful in convincing these people to apply for benefits?

Q7: If you work in different geographies, do you find that different strategies work for people from different places?

Q8: Are there any other strategies or particular talking points you use to convince people to apply who may be hesitant to do so?

Q9: What about strategies that you have used that have been unsuccessful in persuading clients who express hesitance due to stigma to apply for benefits? Do you have an example of such a case?

Q10: Is there anything else you would like to add that we have not already covered?

Endnotes

1   On children and benefits stigma, see Pogash, C. "Free Lunch Isn't Cool, So Some Students Go Hungry." *New York Times.* (March 1, 2008).

2   United States Department of Agriculture. (2015). *Trends in Supplemental Nutrition Assistance Program Participation Rates: Fiscal Year 2010 to Fiscal Year 2013* (Nutrition Assistance Program Report Series). Office of Policy Support: Washington, DC.

3   Falk, G., et al. (December 2015). *Need-Tested Benefits: Estimated Eligibility and Benefit Receipt by Families and Individuals.* Congressional Research Service: (No. 7-5700) Washington, DC.

4   Bruenig, M. (September 2015) *News flash: government spending reduces poverty.* Vox: Washington, DC. Utilizing microdata from the 2015 Current Population Survey, US Census Bureau. Retrieved from *http://www.vox.com/2015/9/16/9341075/poverty-children-elderly-disabled* on March 16, 2016.

5   Center on Budget and Policy Priorities. (2015). "Policy Basics: Top Ten Facts about Social Security." Retrieved from *http://www.cbpp.org/research/social-security/policy-basics-top-ten-facts-about-social-security#_ftn17* on December 1, 2015 and Tiehen, L., Jolliffe, D., Smeeding, T. (2013). *The Effect of SNAP on Poverty.* University of Kentucky Center for Poverty Research-University of Wisconsin Institute for Research on Poverty Five Decades of Food Stamps Conference. No. 1415-13.

6   Gray, A. (2002). Stigma in psychiatry. *Journal of the Royal Society of Medicine,* 95(2), 72-76.

7   Van Doorn, B. W. (2012). Media Portrayals of Poverty and Race in Pre-and Post-Welfare Reform America. In *Annual Meeting of the Western Political Science Association, Portland, OR.* and Iyengar, S. (1990). "Framing Responsibility for Political Issues: The Case of Poverty." *Political Behavior* 12 (1): 19-40.

8   Fields, B. & Fields, K. (2014) *Racecraft: The Soul of Inequality in American Life.* Verso: New York.

9   National Academy of Social Insurance. *Public Opinions on Social Security.* Retrieved from *https://www.nasi.org/learn/social-security/public-opinions-social-security.* November 2, 2015.

10 Smith, T.W., Marsden, P., Hout, M., & Kim, J. (2015) *General Social Surveys, 1972–2014.* The Roper Center for Public Opinion Research, University of Connecticut. Storrs, CT

11 Moynihan, D., Herd, P., & Harvey, H. (2014). Administrative Burden: Learning, Psychological, and Compliance Costs in Citizen-State Interactions. *Journal of Public Administration Research and Theory.*

12 Alaska Department of Health and Social Services. "Food Stamp Benefits." Retrieved from *http://dhss.alaska.gov/dpa/Pages/fstamps/default.aspx* on November 10, 2015.

13 Texas Health and Human Services Commission. "Your Texas Benefits: Getting Started." Retrieved from *https://www.hhsc.state.tx.us/help/1010-eng.pdf* on November 10, 2015.

14 State of Alabama. "State of Alabama—Food Assistance Simplified Application for the Elderly." Retrieved from *http://dhr.alabama.gov/services/food_assistance/Documents/FY_2016/DHR_FSD_2198.pdf* on November 10, 2015.

15 Author's analysis of Mathematica Policy Research and US Department of Agriculture Food and Nutrition Service. (2014). *2013 SNAP Quality Control Data.*

16 US Department of Agriculture. (2015). *Characteristics of SNAP Households, Fiscal Year 2014* (Nutrition Assistance Program Report Series). Office of Policy Support: Washington, DC.

17 Cubanski, J., Swoope, C., Damico, An., & Neuman, T. (2014). *How Much Is Enough: Out-of-Pocket Spending Among Medicare Beneficiaries: A Chartbook.* The Henry J. Kaiser Family Foundation: Washington, DC.

18 Texas Health and Human Services Commission.

19 Kneebone, E. & Berube, A. (2014). *Confronting Suburban Poverty in America.* Brookings Institution Press: Washington, DC.

20 Bettinger, E., Long, B., Oreopoulos, P., & Sanbonmatsu, L. (2012). The Role of Application Assistance and Information in College Decisions: Results from the H&R Block FAFSA Experiment. *The Quarterly Journal of Economics,* 1205-1242.

21 For the most recent list of states, see Food Research Action Center. (2015). "Heat and Eat: State Responses to the Changed Federal Law." Retrieved from *http://frac.org/leg-act-center/farm-bill-2012/heat-and-eat-state-responses-to-the-changed-federal-law/* on December 7, 2015.

22 Enroll America. (2013). "Telephonic Signatures: An Essential Tool for Enrollment." Retrieved from *https://www.enrollamerica.org/telephonic-signatures-an-essential-tool-for-enrollment/* on November 30, 2015.

23 National Council on Aging. (2015). "State Options to Streamline Eligibility for Medicare Savings Programs." Retrieved from *https://www.ncoa.org/resources/state-options-to-streamline-eligibility-for-medicare-savings-programs/* on November 30, 2015.

24 Dorn, S., Buettgens, M., Moody, H., & Hildebrand, C. (2013). *Using past income data to verify current Medicaid eligibility.* Urban Institute: Washington, DC.

25 Moynihan, D., Herd, P., & Harvey, H. (2013). Administrative Burden: Learning, Psychological and Compliance Costs in Citizen-State Interactions. Forthcoming in Journal of Public Administration Research and Theory.

26 Herd, P., DeLeire, T., Harvey, H., & Moynihan, D. P. (2013). Shifting Administrative Burden to the State: The Case of Medicaid Take-Up. *Public Administration Review,* 73(s1), S69-S81.

27 Rowe, G., et al. (2015). *Assessment of the Contributions of an Interview to SNAP Eligiblity and Benefit Determinations: Final Report.* US Department of Agriculture and Mathematica Policy Research: Alexandria, VA.

28 National Academy of Social Insurance. (2014). *Americans Make Hard Choices on Social Security: A Survey with Trade-Off Analysis.* Washington, DC.

About this Report

National Council on Aging