Rewarding, Challenging, and Under Resourced:

A Qualitative Review of the Experiences from Iowa SHIIP-SMP Volunteer Counselors Serving Medicare Beneficiaries

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Executive Summary

For this policy report, The Harkin Institute partnered with AARP and Limelight Insights by Shugoll to conduct in-depth interviews (IDIs) with volunteer counselors supporting the Iowa Senior Health Insurance Information Program (SHIIP) and Senior Medicare Patrol (SMP) office. Participants were asked to share their experiences in providing Medicare counseling and support services to Medicare beneficiaries. Participants were asked about the challenges they face with providing these services, with an emphasis on the unique challenges faced by dual-eligible, lower-income or limited English proficiency (LEP) populations. Within this policy report, our research team shares the key findings and themes from the IDIs and outlines several recommendations for expanding upon (and improving) the quality of service provided to Medicare beneficiaries through the Iowa SHIIP-SMP program. Additional research is needed to better understand the generalizability of these findings for SHIP programs on a national scale.

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Find this report on the web **here.** For more information about the report, contact:

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Introduction

It would prove challenging to find an example of a federal program that has changed more frequently than Medicare over the past decade. Nationally, Medicare Advantage penetration now represents over half (51%) of all eligible Medicare beneficiaries (Ochieng et al., 2023). The number of Medicare Advantage plans available to the average beneficiary in 2024 has more than doubled since 2018 (Freed et al., 2023). The number of dual-eligible Special Needs Plans (D-SNPs) has rocketed to 851 plans in 2024, in comparison to 465 in 2019 (Freed et al., 2023). The constantly evolving Medicare environment has left newly eligible Medicare beneficiaries with a lot of information to navigate in a short amount of time to comply with enrollment deadlines and requirements.

State Health Insurance Assistance Programs (SHIPs) were created under the Omnibus Budget Reconciliation Act (OBRA) of 1990, which authorized grant funding for states to provide advisory services to people covered under Medicare (Centers for Medicare and Medicaid Services, n.d.b.). The role of SHIP has continuously evolved over the years – in addition to providing education/support on Medicare-related issues, SHIP programs also help educate beneficiaries on public benefit programs, assist with resolving Medicare billing related issues, and depending on local structure/funding, may also perform Senior Medicare Patrol (SMP) services to help prevent and report fraud and abuse (Administration for Community Living, n.d.). According to the Administration for Community Living (n.d.), there are 54 SHIP grantees that operate over 2,200 site locations with a network of 12,500 individuals (including staff and volunteers).

While the value of SHIP has been frequently cited in research and literature, there is minimal research examining the unique challenges SHIP counselors face in supporting Medicare beneficiaries. Particularly for SHIP counselors that provide one-on-one support to beneficiaries, there is a need to better understand the challenges beneficiaries face in navigating an ever-changing Medicare environment, particularly for those who are considered vulnerable/underserved or who have limited English proficiency (LEP). The focus of our research at the Harkin Institute is to better understand what those challenges are and to work in partnership with SHIP to develop solutions for strengthening the quality of services provided to Medicare beneficiaries.

For this research study, the Harkin Institute partnered with the Iowa Senior Health Insurance Information Program (SHIIP) and Senior Medicare Patrol (SMP) office within the State of Iowa's Insurance Division. Within this policy report, SHIIP refers to Iowa's SHIIP-SMP office, while SHIP refers to the national State Health Insurance Program. Iowa SHIIP and SMP programs operate over 120 site locations across the state with over 400 counselors that serve roughly 40,000 Medicare beneficiaries per year. The goal was to conduct individual in-depth interviews with a subset of Iowa SHIIP and SMP volunteer counselors to learn more about their experiences in serving Medicare beneficiaries and the challenges they encounter in helping older adults better understand and navigate the complexities of the Medicare program.

Methodology

Research Study Design

The research study design was a qualitative research study with in-depth interviews conducted in partnership with Limelight Insights by Shugoll. The research project was reviewed and determined exempt by the Institutional Review Board at Drake University. Transcripts generated from the in-depth interviews were used for the creation of this policy report. All direct quotes provided within this policy report were abstracted from the transcripts of the in-depth interviews. This policy report includes discussion on the main concepts and themes raised across the body of interviews. The authors attended all interviews and reviewed the transcripts before identifying the main themes from the interviews.

A total of twelve in-depth interviews (IDIs) were scheduled as part of this research study. These interviews were scheduled one-on-one with the Iowa SHIIP counselor and a member of the research team at Limelight Insights by Shugoll. The interviews were conducted virtually, and members of the Harkin Institute research team were invited to attend the interviews for note taking and subject matter expertise/support. The interview guide was organized in two core areas: counselor experience with the services they provide overall and a specific focus on vulnerable groups such as dual-eligible, low income, and limited English proficiency (LEP). The interviews are semi-structured around the two main themes with several prompts included depending on the direction of the discussion. All twelve interviews went through the discussion guide and counselor feedback was recorded on all questions.

Participant Sampling and Recruitment

This research study was designed to solely include volunteer counselors participating within Iowa's State Health Insurance Information Program (SHIIP). To identify potential volunteers to include within the sample, the Harkin Institute research team collaborated with Iowa SHIIP's Director to obtain a list of site locations, which were mapped within each county in the state. The research team sought to ensure there was a mix of counselors participating in the study, with emphasis on having representation from both rural and urban communities, in addition to SHIIP offices that are located in more diverse regions of the state. To support this work, the researchers used 2020 Census data to identify the ten most populated counties in the state while also using 2018 Iowa SHIIP data to identify counties with the lowest percentage of white residents. The finalized map is provided in the Appendix.

After reviewing the data, the research team narrowed down the sample to include seventeen Iowa SHIIP office locations. Ten of the locations were in urban areas with the remaining seven in rural locations. A list of counselors at each of the seventeen locations was made available to the research team for recruitment efforts by the Iowa SHIIP Director. Volunteer counselors received an email about the study with the option to opt out from the recruitment. The final list of counselors invited to participate in the study included seventy-seven individuals.

For the in-depth interview (IDI) component of this research study, the research team established twelve IDI slots. All volunteers working out of the seventeen SHIIP office locations included in the sample were contacted via email by Limelight Insights by Shugoll to participate in the study. Interested participants were successfully recruited for the study until the twelve IDI slots were filled. Each participant was then scheduled to attend an hour-long IDI with a researcher from Limelight Insights by Shugoll.

The final sample included counselors from seven urban sites and five rural sites. Their experience ranged from 1 year to over 10 years of experience, with the most common level of experience being 2 to 4 years (6 counselors). The majority of counselors are retirees, between 65 and 74 years old, and they have a variety of professional backgrounds including health and financial services.

Key Findings

SHIIP-SMP counselor training and experience with the counseling workload

The participants within this research study were asked to share their experiences with training to become a SHIIP-SMP counselor. Before volunteers can begin providing counseling services to Medicare beneficiaries, volunteers are required to complete the education and training necessary to obtain certification. SHIPs have the flexibility to choose their own volunteer training and certification methods, so this may vary from one state to the next. According to the Iowa SHIIP-SMP website (2022), counselors are required to complete the initial new volunteer certification and then must recertify annually.

For the initial volunteer certification, counselors complete online courses and virtual training sessions. They are then required to shadow an experienced SHIIP-SMP counselor to observe counseling sessions and learn more about the reporting requirements. Once they have completed the training, they are required to complete a minimum of 30 client contacts during their initial year in the program.

For the annual recertification, counselors must complete virtual spring training sessions (up to five are provided per year) and all-day training in the Fall (which may be completed in person or by watching recorded sessions), complete a confidentiality training and pass an online certification review. Starting in the second year, counselors complete a minimum of 60 individual client contacts each year.

Several participants provided feedback on the rigorous training provided to new volunteers. The participants discussed how the objectives of the initial training sessions were to cover the "need to know" items for Medicare, providing a more general well-rounded education rather than focusing on specific issues. Several participants commented on the amount of information being shared and the challenges with remembering everything, particularly when dealing with issues that volunteers are not regularly exposed to.

"They have one training a year where everyone comes in face-to-face. It's when we're getting ready to roll out open enrollment, and they're updating us on all of the new plans. And there's case studies. And there's conversation. And it's a whole-day thing. And that's a good thing." **-Counselor ID1**

"I mean each year we probably have five training sessions we go through. They're all on Zoom now, except for the one meeting we have right before enrollment. There is a lot that you have to keep up on, and after each one, you take a test, and you have to pass the test. For me, a part of it is if you aren't doing a lot of some type of counseling, say if you don't have a lot of Medicaid people, or you don't have a lot of people that need the D-SNP, it's hard to keep up on that. I mean you go through the training, but if you don't use it very often, and that's one thing, we don't see a lot of those people at our facility, so we need additional help at times. The ones who are having problems, those are the hard ones, and those are the ones you don't do very often." **-Counselor ID7**

"Volunteer training is now done online. It's six weeks. It's modules. Volunteer training when I did it was in-person, five business days. They said we're going to teach you the stuff that you're most likely to talk about; otherwise, here are two huge notebooks and call our volunteer line." **-Counselor ID8**

"This is like going back to college. It really is. It's like. "Oh geez. This is a lot." And I think part of that was the training online. And then we would have a meeting with the instructor. And then after that, we would have homework to do. And we would have Zoom meetings twice a week. And in-between that time, we'd have nine sessions we had to listen to online, and do a quiz on. And it's like, "Oh my gosh. I don't think my brain can hold all of this." **-Counselor ID10**

In addition to sharing their perspectives on the amount of training and education provided to counselors during the initial training period, several participants commented on the amount of work and expectations placed on individuals that approached Iowa SHIIP-SMP for a volunteer position. The participants discussed how volunteers would withdraw from the program or express remorse after realizing how much training and effort went into a volunteer position. Several comments were shared regarding the overwhelming amount of information provided and the amount of time expected to be committed to counseling.

"I've been training, on the average of one new counselor a year since I started. And they usually, by the open enrollment, they're like, "Yeah, this is more than I thought it was going to be. I can't do it." Because we do a recertification every year. We've got mandatory trainings. And we have trainings that are available, but they're not mandatory, that we can go to. And so if a person isn't interested in understanding more, they just want the basics, they're good with that. But then they have to refer everything if they don't understand it." **-Counselor ID5**

"The problem as I see it is that it's the time. It's too consuming of a volunteer role. A lot of people just don't want to dedicate that much time to something that's a volunteer position." **-Counselor ID5**

"I mean there is a very overwhelming element to the initial training. There's almost an over-emphasis on making sure we have everything. And it's impossible to get. There is a sense of the initial training that "We want to give you a little bit of everything about Medicare." **-Counselor ID6**

"I think the challenge there is that any of us could see a slightly different slice of the population. And I think the other challenge is that for new counselors, giving them the full gamut is just overwhelming. And I think we've lost some people because they get into it and realize this is way more than what they were prepared for. It's very hard, in some of these more technical areas, to be able to on-the-fly snap into that information and be as effective as you want to be." **-Counselor ID11**

Referrals to SHIIP-SMP counselors

When asked about how Medicare beneficiaries learn about Iowa SHIIP and the unbiased services and resources that are available within the program, many of the volunteers talked about the informal referral methods that are frequently cited in research – for example, referrals to Iowa SHIIP from family,

friends, or acquaintances that have used SHIP services in the past. However, several volunteers also provided insight into more formal referral arrangements that are in place.

For example, there was discussion on referrals from healthcare providers (e.g. physicians and pharmacists) that were uncomfortable with answering Medicare-related questions.

> *"A pharmacist gets pretty well inundated. And so if they can ship them off to us, transfer them over to us, that works."* **-Counselor ID9**

> *"I get a lot of referrals from the doctors right here at the Medical Center, because they don't know. They don't know about Medicare and Medicaid and all of that. And a lot of the people that I see say that their doctor said they should come see me."* **-Counselor ID10**

One participant discussed the frequency of insurance agents referring beneficiaries to SHIIP to learn more about the program before making a decision on policy enrollment.

> *"People go to talk to an insurance agent about a supplement or Part C. A lot of times the insurance agents will refer them to SHIIP to get a better understanding of what they want to do before they sell them any policies."* **-Counselor ID4**

Another participant discussed receiving referrals from federal entities, such as Social Security and the Iowa Department of Health and Human Services, to provide one-on-one support for beneficiaries that prefer face-to-face guidance and support.

> *"I get referrals from Social Security and the Department of Human Services to do the one-on-ones with people, rather than them. And I don't know if it's because these people want to sit face-to-face and they don't have that ability, or if they just think, "Oh heck. We'll just send them on over there. They'll fill out the application for them." I mean I get a lot of people who are like, "Well, they told me to come here." And so I help them."* **-Counselor ID5**

Several participants also discussed the referrals they receive from HR departments with local employers once employees make the decision to retire and want to learn more about Medicare enrollment as the replacement for their private insurance coverage through the employer.

> *"For a while I was getting a lot of that clientele from <redacted> University, which is about 15 minutes from here. Someone who worked in their HR office used to send people up here. I think she still gave them a little spiel about you're going to make a decision by this time and here is some stuff that's <redacted> related, like only I can talk about, but then I think she gave them 18 words on Medicare and said if you have any other question, go up there."* **-Counselor ID8**

> *"I know that the benefits office, for example, at the University is very happy to refer people to SHIIP because they don't have the resources or the knowledge or desire to really try to fill that niche. Their focus is on active employees. Once people are retired and on Medicare, that's outside of their mission."* **-Counselor ID11**

Through analysis of these interview responses, it is apparent that Iowa SHIIP is successful in its mission to provide Medicare counseling and resources to Iowans. As evidenced by the feedback shared from our research participants, Iowa SHIIP is a trusted resource not just for Medicare beneficiaries, but also for healthcare providers and community organizations where there are in-house resource limitations for providing proper guidance and support. Participants in this study described how these referrals typically work, giving the impression these referrals are somewhat informal or unstructured. Based on the accounts, individuals are told to contact Iowa SHIIP, but that connection is dependent on the beneficiary obtaining the contact information and initiating the connection – there does not appear to be a formal or structured referral process in place for connecting the beneficiary to Iowa SHIIP.

Challenges with D-SNP

As part of our focus on vulnerable populations, the interview guide included questions about the counselors' experience with beneficiaries who potentially qualified for dual eligible special needs plans (D-SNPs). D-SNP plans are a subset of Special Needs Plans specifically targeted for individuals that are considered dual eligible (meaning they are eligible

for both Medicare and Medicaid). These are Medicare Advantage plans designed to integrate and coordinate Medicare and Medicaid benefits. According to Justice in Aging (2024), D-SNPs are the largest category of special needs plans growing from 2.5 million enrollment in 2019 to 5.2 million enrollment in 2023, and they account for half of the total Medicare Advantage enrollment.

Populations that are dual-eligible tend to require more support both financially and clinically in comparison to non-dual-eligible Medicare beneficiaries. For example, a recent study from the Kaiser Family Foundation (2023) found that:

- 87% of all dual-eligible enrollees had an income of less than $20,000 compared to 20% of Medicare beneficiaries that did not qualify for Medicaid coverage.
- 44% of dual-eligible enrollees were in fair or poor health, in comparison to 17% of Medicare beneficiaries that did not qualify for Medicaid coverage.
- 48% of dual-eligible enrollees had at least one limitation in activities of daily living, compared to 23% of Medicare beneficiaries that did not qualify for Medicaid coverage.

While research shows D-SNP enrollment growth is steadily rising, the volunteers within our qualitative study highlighted the knowledge gap that exists for new Medicare beneficiaries in understanding how dual eligibility works and the requirements for qualifying in the program.

"Generally, if they're on it, they know about it. If they're not on it, no, they have no clue. That's where we start helping walking through. And we help get them signed up." **-Counselor ID1**

"You might ask, but generally they don't know. You can say that for that whole population. They are lacking and knowing… "Knowing" might not be the right thing. They have been told. They may have been exposed to it. But I wouldn't say they have a very good working knowledge." **-Counselor ID9**

"Medicaid can be a tough system to deal with, and there's lots of paperwork, and there's lots of things that you have to keep track of. And often, people are really not aware that they have some additional resources available to them. So, especially people, maybe, who have been on Social Security Disability for a couple of years, and now, because they've been on for twenty-four months, all of a sudden, they get a letter and it says well, you have to sign up for Medicare now. And they're like what? I thought I had Medicaid." **-Counselor ID12**

Another issue raised during the IDIs highlighted inefficiencies/flaws in the process of transitioning beneficiaries from Medicaid to Medicare once they reach the age of 65. For states that expanded Medicaid under the Patient Protection and Affordable Care Act, the extended eligibility only applied for individuals under the age of 65 (Medicaid and CHIP Payment and Access Commission, 2023). Once reaching age 65, eligibility requirements may change (this varies by state) and beneficiaries may be surprised to learn they are no longer eligible for Medicaid coverage.

"If there's one particularly frustrating element of all of this, and the frustrating list is a very long list. But mostly, it's how poorly… And this is not limited to Iowa, I don't think. But, it's how poorly we transition people from Medicaid to Medicare. Particularly since, as you probably are learning, invariably, if you're on Medicaid, as you approach your 65th birthday, Medicaid sends you a letter that basically says, "Your benefits end." I think they may encourage them to call SHIIP. But they do not mention that there are further Medicaid programs that they're eligible for after 65 like the D-SNP, Medicare Advantage plans and other Medicaid assistance plans that, and the goofiest part, that we then reapply back to Medicaid for these people to get on those programs. And it seems to me that that transition could be much smoother on Medicaid's part of saying. "Your full Medicaid benefits end. You're eligible for Medicare. But you're also eligible for some additional Medicaid assistance. And so we're going to reclassify you. Because, they have all of the information." **-Counselor ID6**

One final issue highlighted during the IDIs touched on the confusion associated with the unwinding of Medicaid waivers post-COVID. At the beginning of the COVID pandemic, the

Families First Coronavirus Response Act (FFCRA) established a continuous enrollment requirement for state Medicaid programs to ensure beneficiaries did not lose coverage during the COVID-19 public health emergency (Tolbert & Ammula, 2023). This continuous enrollment provision ended in March 2023 which allowed states to resume their typical Medicaid disenrollment processes (frequently referred to as Medicaid unwinding). According to Iowa SHIIP volunteers, this unwinding process led to confusion amongst beneficiaries.

> *"Most of the people I see who are on Medicaid are the ones who are losing Medicaid, and so their income is just over the limit. After COVID, Iowa has thrown off a lot of people in the last year. So this year, it's the first time they've heard they are no longer eligible. Iowa has done this to a lot of them. I think a lot of them got thrown off because they didn't see the letter that said that they were being thrown off. You know, a lot of them do not look at the mail they get, so they got some letter from DHA and they threw it out."* **-Counselor ID7**

Unique challenges for low-income beneficiaries

During the qualitative IDIs, Iowa SHIIP-SMP volunteers were also asked about their experiences in working with low-income beneficiaries and to share any unique challenges these populations face in navigating the complexities of Medicare enrollment. According to the Harkin Institute's review of the Iowa SHIIP-SMP database (where Iowa SHIIP-SMP volunteers document their encounters with Medicare beneficiaries), 19% of older adults that received services from Iowa SHIIP were classified as being below 150% of the federal poverty line.

Several volunteers highlighted the technological challenges these populations face. Volunteers mentioned recurring issues such as lack of access to a computer or mobile device and lack of access to internet. These technology barriers result in many challenges with completing the requirements for enrollment, as many volunteers touched on systems requiring access to a computer or mobile device.

> *"Well, most of them at that level in my area, they don't have internet at home. They don't have a computer. A lot of them do not have a Smartphone. And so they have no way of doing these things on their own because now everything is electronic, since COVID."* **-Counselor ID5**

> *"Some of them don't have an email address. And they're going to have to have that. They need two forms of identification. If they don't have it, sometimes I have to set it up for them on their phone. Other times… Like I had a lady I was helping. And she was around my age. And I've known her for a long time. And I said, "Do you have an email." And she goes. "No, but I'll have my daughter get me one." And so her daughter had it all set up. But sometimes when they come in, they don't even have a phone that's capable to get an email on it."* **-Counselor ID5**

> *"We have a lot of Mennonites in our area, which are… We have the Amish. We have a lot of Amish. But they pretty much don't pay taxes. But we have a lot of Mennonites who have paid into the Social Security system. And they're the ones, they'll have a flip-phone. Those folks are probably the most technologically-challenged that we have. They have no internet, no computers. And so I would do more for them as far as getting things set up than I would for your average person, especially if I know the person and I know that they have some resources, like they've got children who could help them do these things."* **-Counselor ID5**

> *"They struggle with working with computers. I mean they don't have a computer. They don't own a computer. And that's okay. Now, I can't say that about everybody within the 150%. But a lot of people don't own computers. They don't know how to work computers. And the whole system is pretty much computer-based."* **-Counselor ID9**

Another challenge cited by Iowa SHIIP-SMP volunteers centered around difficulties with understanding how to calculate or quantify necessary metrics for eligibility, such as total income, retirement accounts, and other investments.

"Helping them understand how to calculate their income. They don't always understand gross versus net, how that impacts, what they need to watch out for, making them understand what resources are. Do you have a savings account? Do you have a pension? Do you have a 401K? Do you have any stocks or bonds?" You have to walk through every bit of it. Because if you're trying to get them on LIS and stuff, all of this is important. My easiest one says, "I don't have anything but what I get each month." "Okay. We're good to go. Let's start rolling." **-Counselor ID1**

"We have actually a card and a sheet that shows the income levels that people need to qualify for the different programs. It's almost universal that people don't know their exact income or their resources. The resources are confusing because their personal home is not included and one car. People are not sure what they have…if they have a savings account or if they have a retirement program, those are going to be included in resources. People often as I go through the checklist on their income and resources, they don't really know what they have. Those people I often direct to Department of Human Services and tell them they have to take in all their bank statements for three months and their last three years' tax returns and any other listing of resources that they have and see what they can qualify for." **-Counselor ID4**

Iowa SHIIP-SMP volunteers also highlighted how some older adults struggle with medical conditions that affect their ability to sit through the SHIIP counseling and can lead to barriers for fully engaging in the support available. Some of the medical issues cited were health issues that affect the ability to sit for long periods of time, challenges hearing over the phone due to auditory conditions, or other conditions such as dementia.

"People may not understand that there are pieces they have to pay for. It's just a huge number of decisions. I'm thinking of people, for number one, don't have English; number two, have very bad health issues; that may be just sitting and being there for an hour, it's very hard on them. I could only say thank heavens for their children who are often the ones that we end up working with. But yes, this is a population I'm very concerned about." **-Counselor ID3**

"Well, a lot of these folks who are in the category also are not comfortable doing it over the phone. Some of them, they have communication issues. They don't hear well. And of course, they can't afford hearing aids. And those aren't covered by any Medicaid services. And so, they can't hear. And so they want to be in an office in a one-on-one situation to fill out that stuff." **-Counselor ID5**

"I've been doing it a long time so I know my people who are hearing impaired or have dementia; people that I know are not going to be able to deal with this unless they sit down face-to-face. They couldn't Zoom because they couldn't get to this point. They're not going to be able to call 1-800-Medicare. I really try to get those people to get booked with me early." **-Counselor ID8**

Several research participants highlighted the unique challenges some beneficiaries face when they fall within the "gap" from an eligibility perspective. These are the beneficiaries that do not qualify for assistance, yet do not have enough financial resources to obtain the coverage they need. Several Iowa SHIIP-SMP volunteers expressed their concern about financial limitations impacting the ability of Medicare beneficiaries to choose the coverage option that is optimal for them – instead finding themselves limited to selecting coverage options they could afford in the present time.

"I think the most significant challenge to that population is for all intents and purposes, Medicare Supplements is not an option they can consider. The cost just takes it out of it, so that you don't even get a chance to really explore the benefits of a supplemental plan versus… I mean obviously… The most obvious constraint on Medicare Advantage Plan is they're networked. Right? You have to see the network. And one of the bigger benefits of Original Medicare and a supplement is the network is everybody. Right? You don't have to worry about what doctor you have to go to. You don't have to worry about referrals. You get your red, white, and blue card. Everybody takes it. But for folks in that income category, there's enough of a challenge to pay this $175 without looking at adding to that. It's just not a feasible option for those folks. And I think that's unfortunate." **-Counselor ID6**

"I have a lot of farmers in the area that have been through a lot of farming crises. And the wife maybe did not work away from home. And so they just struggled by. And now they're retired. Maybe they rented land. They didn't own land. And so they're struggling now because they didn't pay much into Social Security. And so they're not getting a lot back." **-Counselor ID10**

"Frankly, the ones that I find the most difficult are the ones that are just above the threshold that don't quite qualify, but clearly have financial needs. And yet they don't qualify for the programs as they are currently structured. And I find that very frustrating. Or for example, I had an individual who had been on full Medicaid I believe, turned 65 and was no longer eligible for it, and had no understanding for why because his income hadn't changed, his circumstances hadn't changed, but the criteria on which his eligibility was being based had changed because of his age. And so helping him to understand; okay, we're not going to fight the battle here." **-Counselor ID11**

"Low income is, you know, it's a struggle for these folks. You know, they are on a very fixed income, and they are very concerned about what their Medicare coverage is going to cost them, how can they afford it if it's not covered by Medicare, you know, if they've got really expensive prescriptions. So, obviously, setting them up with any of the extra help programs and financial programs available. But I think that the population that really struggles are those that are just above the cut-off guidelines for the assistance. You know, because they may have what looks like a pretty good income, but, you know, they may be raising grandkids. You know, they may be, you know, having to pay off an old debt. So those are a challenge, because they're like well, I want whatever's going to cost me the least amount of money. You know, well, that can get to a scary area. So, I think those are difficult because you wanna do the best you can for 'em, but at the same time, you don't wanna leave them not adequately covered for their needs." **-Counselor ID12**

One final discussion point shared by participants in the study centered around the social stigmas associated with accepting assistance and how this influences the decision-making process for newly eligible Medicare beneficiaries. The study participants noted how public perception affected the willingness of Medicare beneficiaries to discuss assistance programs, particularly if the beneficiary was concerned about people knowing they qualified for assistance.

"If they have problems, usually when they come in, it's not because they're just signing up for Medicare, but it's because they have some problem. Some may not have gotten paid, or many of the ones I see is because they're losing part of their coverage. Maybe they're no longer going to be on Medicaid. There are some people who don't want to go on Medicaid because they don't want the stigma. Nobody knows, but they don't want to. Or, they don't want to get the special help through Social Security for drugs, which is more likely for people to do." **-Counselor ID7**

"Some of them more demoralized people because either they've gone through a lot to get the coverage that they have, or even if it was a relatively straightforward process for them, the societal pressure here against taking any help is real. They're like don't tell me options; it's bad enough that I have what I have; I certainly don't tell people that I have low-income subsidy or Medicaid…whatever program. However they're getting help, they really don't want people to know about it." **-Counselor ID8**

Unique challenges for ESL beneficiaries

Iowa SHIIP-SMP counselors were also asked about their experiences working with beneficiaries that spoke English as a second language (or have limited English proficiency, LEP). According to Iowa SHIIP data, 17% of older adults assisted by Iowa SHIIP spoke English as a second language. When asked about the unique challenges these beneficiaries face in receiving Medicare enrollment assistance, a majority of the study participants stated they rely heavily on family members or friends to help translate. Even when translation services/ technology are available to support communication, Iowa SHIIP volunteers expressed the preference of working with an actual person to help translate with a few study participants noting challenges that arise when attempting to use an external translator.

"They actually give us a service that can interpret for us. Luckily, I didn't need that because his daughter came. And she was bilingual. And it worked beautifully. He did not understand a word I said. And so she was interpreting. We were going back and forth. But she was understanding everything." **-Counselor ID1**

"My experience has been always to have a family member as an intermediary. And the family member was a dual-language speaker. And so I would explain things to the family member. And then they would turn around and explain it to the other person." **-Counselor ID2**

"Usually, most of the ones I see are Chinese, and they always bring someone with them. Sometimes it's a friend. Sometimes it's a daughter or son. Sometimes it's just someone who works with them. I've never had anybody come in that I had to speak with directly and they didn't understand." **-Counselor ID7**

A few Iowa SHIIP-SMP counselors discussed the resources available to them at the location where services are provided. For example, volunteers working out of a hospital are able to request the use of hospital interpreters to help support beneficiaries that speak other languages. This seems to be part of the mutually beneficial relationship between Iowa SHIIP and external entities – SHIIP counselors have access to resources at the hospital to support their work, in exchange for helping Medicare patients better understand their coverage.

"This may have something to do with the location that I'm in, but this is a community where we have many immigrants who don't necessarily speak English. And so, we have only a very few things that are in Spanish, and certainly, we don't have anything in Lao, and we're sponsored by the local hospital, which has interpreters, but they are often very busy and may not actually be available when I need them." **-Counselor ID3**

"Another advantage of being at the hospital, the hospital is such a wonderful support for me. They have interpreters here. And I can use them anytime I need them." **-Counselor ID10**

A few specific issues were raised as it relates to the materials and support available for beneficiaries that have limited English proficiency. One of the primary concerns shared centered around the lack of available resources in the beneficiary's preferred language. When resources were available, sometimes regional dialects would create additional challenges with being able to support these populations.

"Language barrier. Just because I speak Spanish and they speak Spanish, we may not be from the same region. And so there's always going to be that. We do have resources at our office. And they did ask me… This is the one time I said no. They asked me if I would be on their list as an ESL translator for Spanish. And I said, "No, I'm not comfortable, because of the different dialects." **-Counselor ID5**

Another issue raised by Iowa SHIIP-SMP counselors related to the perceived gaps in outreach for beneficiaries that speak English as a second language. Throughout the IDIs, several volunteers discussed how awareness of Iowa SHIIP largely results from word-of-mouth advertising and connections to their office from those who have previously used Iowa SHIIP (or heard stories from others who used the service). One participant mentioned the number of ESL beneficiaries seeking help from Iowa SHIIP would look different if there were better resources in place to support this population (more specifically, counselors in-house that spoke the same language).

"We have a couple of options for interpreters if we don't have a real person. We've got a thing on the telephone, a machine, but those are hard for me, and that's about me, not about them not being good. Those are populations that we're not reaching out to adequately. I am very clear about that." **-Counselor ID3**

"I think if it's not the primary barrier, it's certainly the second is that we have 99% English-speaking counselors. If you go back and think how do people get here, how are they ending up at SHIIP, it's because of friends, providers, and employers. And so if there were counselors who spoke different languages based on those organizations, then those numbers would look very different." **-Counselor ID6**

Discussion and Recommendations

Throughout the in-depth interviews conducted with Iowa SHIIP volunteer counselors, there were several common themes and issues highlighted by our research participants. Many of the participants highlighted the great service SHIP provides nationally for assisting Medicare beneficiaries with better understanding their coverage options and the financial impact of enrollment decisions. Participants also discussed the resources and support provided by Iowa SHIIP to help make their jobs easier and the resources available at the Des Moines office to help when working with beneficiaries that have complex needs beyond what the volunteer is able to support independently. Additionally, participants in our study helped our research team better understand the "gap" Iowa SHIIP helps to fill in the community for providing one-on-one education and support not just for Medicare beneficiaries, but also for community partners and organizations that are unable to provide the same level of support in-house. The in-depth interviews also brought to light the unique challenges certain populations face when approaching the Medicare enrollment period, with emphasis on those who are transitioning from Medicaid to Medicare at age 65, those who are underserved or under-resourced, and those with limited English proficiency.

As a result of the feedback and insight provided by Iowa SHIIP volunteer counselors, the following recommendations were drafted by the Harkin Institute research team as strategies to help overcome the challenges shared. The first recommendation focuses on building stronger referral pathways to help support outreach and engagement efforts, seeking to provide a more direct point of access for SHIP services in partnership with community organizations. The next recommendation seeks to improve the experience of Medicaid beneficiaries in transitioning to Medicare at age 65. The final two recommendations focus on providing a response to two of the common themes shared during the in-depth interviews: (a) improving financial planning and retirement fluency among newly eligible Medicare beneficiaries; and (b) strengthening community partnerships to better support beneficiaries with limited English proficiency.

Recommendation #1: Developing a more formalized pipeline for connecting newly eligible Medicare beneficiaries with Iowa SHIIP.

One common theme shared by several participants within this research study was the value of Iowa SHIIP as a referral partner for various entities (both public and private). With the complexity of the Medicare program, it is understandable external organizations would value a partnership with Iowa SHIIP to help answer and address questions or concerns from newly eligible Medicare beneficiaries as they prepare to make initial enrollment decisions. Based on our conversations with Iowa SHIIP- SMP counselors, these referrals tend to be relatively informal and newly eligible beneficiaries are required to initiate the contact with Iowa SHIIP to close the referral loop. With this in mind, there is an opportunity to strengthen the referral process by establishing a more direct referral pipeline between external entities and Iowa SHIIP.

For example, several participants mentioned how local community partners will refer newly retired employees to Iowa SHIIP to help answer questions and concerns about Medicare enrollment, while also helping with answering questions beneficiaries may have as they prepare to transition from the employer's private insurance coverage to Medicare or Medicare Advantage. Rather than advising the individual to reach out to Iowa SHIIP on their own accord, a referral pipeline could be established where the external organization connects directly with the Iowa SHIIP office to complete the referral, allowing an Iowa SHIIP volunteer from the designated location to contact the beneficiary and initiate the counseling support.

A stronger referral pipeline could provide many benefits, particularly for supporting vulnerable and/or underserved populations. A stronger referral loop helps with ensuring beneficiaries are connected to Iowa SHIIP by removing the expectation for the beneficiary to initiate the contact. Additionally, as evidenced by the feedback shared by research participants within this study, some beneficiaries lack access to resources such as phones and computers, which may result in challenges with locating and contacting Iowa SHIIP. Lastly, stronger referral pipelines can lead to more consistent outreach and engagement with newly eligible Medicare beneficiaries, which would ideally help with promoting and marketing the services of Iowa SHIIP.

An emphasis on strengthening referral pipelines would align with evidence-based recommendations for better supporting individuals enrolled in public insurance. For example, referrals to social services and community-based organizations (CBOs) has been cited as a strategy for assisting Medicaid beneficiaries with overcoming challenges related to social determinants of health (Hinton & Diana, 2024). Additionally, a direct pipeline would help reduce the likelihood of employers and other external entities providing unofficial enrollment education and advice due to lack of access to CMS-approved educational materials (Better Medicare Alliance, 2021).

Recommendation #2: Enhanced education/ support for helping beneficiaries better understand the transition from Medicaid to Medicare and the Special Needs Plan options available.

While SHIP volunteers receive extensive training on issues and topics related to Medicare and Medicare Advantage, the participants within this research study expressed lower levels of familiarity (and comfort) with Medicaid programs. When asked to share their feedback on opportunities to better support beneficiaries, several volunteers highlighted the need for improved coordination between State offices in supporting beneficiaries with the transition from Medicaid to Medicare.

> *"I don't know if this is within SHIIP's capacity, but I think both statutorily or politically, but I would think SHIIP is a part of the Insurance Division, which is part of State government. Medicaid is a program of State government that there ought to be a way to move the conversation within State government about this transition from Medicaid eligible people to Medicare."* **-Counselor ID6**

> *"I think most of the DHS offices know about us and will send people, will direct people to us, because, you know, people do applications for Medicaid all the time and get denied. So, you know, it would be good if they're saying, you know, no, you're not eligible for Medicaid, you know, maybe you should talk to a SHIIP counselor about could you do something better with your Medicare coverage or is there another option for you."* **-Counselor ID12**

A few Iowa SHIIP-SMP volunteers also mentioned the lack of resources available for helping retirees better understand the Special Needs Plans available and the eligibility criteria for those SNPs. Additionally, these volunteers highlighted a need for more training and education to better prepare counselors for talking through SNP options and addressing Medicaid-related questions from beneficiaries.

In designing improvements for supporting these beneficiaries, it may prove valuable to follow the recommendations developed by California's SHIP program, referred to as HICAP. In a 2021 study of California's HICAP, a need was discovered for establishing a roadmap in partnership with State offices to improve how the HICAP office served dually eligible populations (Janoski, 2021). Through collaboration with the Department of Health Care Services, it was determined HICAP could improve the knowledge of volunteers for enrollment processes while also establishing clear expectations and guidance on how volunteer counselors could support dually eligible individuals (Janoski, 2021).

A similar recommendation could be followed for Iowa SHIIP in developing a more structured roadmap in partnership with the Iowa Department of Health and Human Services. Within this roadmap, additional resources could be developed to help beneficiaries better understand the transition from Medicaid to Medicare once the individual turns 65 while also strengthening the resources/support available for Iowa SHIIP volunteers to help improve the counseling support provided in areas related to D-SNP model requirements, care coordination, and integration of Medicare and Medicaid for beneficiaries eligible under SNPs.

Recommendation #3: Additional resources for financial planning and/or planning for retirement to help beneficiaries nearing retirement better understand what they may qualify for.

Another common theme highlighted across the in-depth interviews centered around low levels of financial literacy for beneficiaries receiving support from Iowa SHIIP. When asked about the challenges underserved and vulnerable populations face in particular, several research participants noted the difficulty beneficiaries face in calculating their basic finances and challenges with understanding the costs associated with retirement and/or Medicare enrollment. While this is

an issue that affects beneficiaries across the spectrum, it is particularly concerning for older adults with limited incomes and fewer assets to cover the costs associated with medical treatment and Medicare coverage.

These findings shared by our research participants align with the literature as it relates to financial literacy and retirement fluency. According to TIAA, retirement fluency refers to the knowledge one needs to promote financial well-being in retirement (Yakoboski et al., 2024). According to TIAA's most recent Personal Finance Index, a majority of Americans make financial decisions with a poor level of financial literacy (Yakoboski et al., 2024). On average, adults correctly answered 48% of the index questions in 2024, a figure that has consistently hovered around 50% since the survey was first released in 2017. The survey also shows older adults struggle with retirement-related topics, with respondents only answering two out of five questions correctly on average.

While our research study points to the need for more education and support on Medicare enrollment topics specifically, the feedback from our research participants also indicates a need for more resources and support in helping older adults better understand their financial situation and how that will impact their needs for retirement. Several participants in our study discussed their process of helping counsel beneficiaries on their finances and better understanding how their Medicare enrollment decisions impact their long-term financial outlook. Several participants also expressed concern about beneficiaries making enrollment decisions based on what is most affordable in the present and the long-term financial impact this could have on the beneficiary by choosing a suboptimal coverage option due to financial resource limitations.

Specific Medicare-related information materials could include a brochure with several scenarios for coverage under traditional Medicare compared to Medicare Advantage plans for up to three hypothetical income groups, that also includes both premium costs and out of pocket costs. It remains a significant challenge to address how individuals could be better prepared to identify resources available to them, particularly in light of the complexity of employer retirement programs. For those who have some of those resources, they may have had inconsistent access and may have left retirement savings with former employers. In many instances, they have not worked with a financial planner who can help them track such resources. Other countries have implemented retirement savings dashboards, where these accounts can be tracked by individuals, and in some instances consolidated. Another way to address this problem on a more global policy level is to remove asset limits for these programs, including retirement savings and other long-term savings accounts, which are needed for the retirement security of individuals (Prosperity Now Scorecard, n.d.).

Recommendation #4: Enhance community partnerships to close the language gap and strengthen outreach to ESL populations.

Several participants in the research study noted the unique challenges individuals with limited English proficiency (LEP) face when seeking Medicare counseling. While experiences varied for our participants based on population demographics, a recurring theme was the dependency on family, friends, or acquaintances to serve as interpreters. A few volunteers mentioned having access to interpreters at the satellite location in which they provide counseling, but a majority of the participants appear to rely on individuals that are most likely not considered to be qualified interpreters or translators.

While these family members and acquaintances help fill the gap in addressing language barriers, there are concerns about how the use of unqualified interpreters/translators can affect the quality of counseling provided. For example, Section 1557 of the Affordable Care Act established requirements for covered entities (defined as those who administer health-related programs and receive HHS funding) to use only qualified interpreters or translators to support patients with limited English proficiency, clarifying that being bilingual alone is not enough to meet the definition of qualified (National Immigration Law Center, 2024). While SHIP programs would not be considered covered entities under this policy, the use of unqualified interpreters or translators poses obvious concerns with the quality of translation being provided, particularly in discussing the complexities associated with Medicare enrollment and coverage plan options.

There are a few potential solutions for addressing the challenges shared by our research participants. The first solution centers around diversifying the counselor workforce

within Iowa SHIIP. This would align with recommendations from the Centers for Medicare and Medicare Services (CMS) in providing culturally and linguistically appropriate services (CLAS) for beneficiaries with limited English proficiency. One resource published by CMS for certified application counselors (CACs) and navigators for the federal Marketplace centered around counselor education in addition to "taking steps to recruit, support, and promote a staff who share demographic characteristics with the communities they are serving" (Centers for Medicare and Medicaid Services, n.d.a.). Particularly for satellite locations operating in more diverse regions in Iowa, engaging with community partners to identify and recruit a more diverse volunteer workforce would help address some of the challenges shared by volunteers.

However, recruitment for volunteer positions may prove challenging. Thus, SHIP offices should also explore efforts to enhance community outreach and engagement. Several research participants expressed concern about not effectively reaching populations with limited English proficiency. While there is limited research on this issue for Medicare beneficiaries specifically, a publication from the National Immigration Law Center (NILC) focused on the challenges Medicaid beneficiaries face in navigating Medicaid resources and completing enrollment requirements. Within this publication, the NILC highlighted a partnership between health centers serving Asian populations and California's Children's Health Insurance Program (CHIP) to increase enrollment rates of Asian children (Lessard & D'Avanzo, 2024). More specifically, NILC recommended partnership with community-facing organizations like community health centers, faith-based organizations, and schools to better support Medicaid beneficiaries in navigating program requirements (Lessard & D'Avanzo, 2024).

These same lessons could be applied for strengthening Medicare counseling for SHIP programs nationwide. The development of mutually beneficial partnerships with community entities that serve Medicare beneficiaries can help strengthen the outreach and engagement efforts for limited English proficiency populations. For example, opportunities to partner with local Federally Qualified Health Centers (FQHCs) can result in a more direct line of access to diverse populations. FQHCs serve as vital safety net providers for Medicare beneficiaries, with the number of Medicare beneficiaries supported by FQHCs doubling since 2010 (National Association of Community Health Centers, 2024). According to 2023 Uniform Data System (UDS) data, which is a core set of information reported by FQHCs annually, 63.48% of patients treated at FQHCs nationally were classified as racial and/or ethnic minority patients (Health Resources and Services Administration, 2023). Exploring partnerships with FQHCs could lead to more effective outreach and engagement efforts for connecting newly eligible Medicare beneficiaries to SHIP counseling services.

Conclusion

Nationally, older adults rely on SHIP offices to help with navigating the many complexities associated with Medicare enrollment and planning for healthcare expenditures in retirement. According to the Administration for Community Living (ACL), SHIP connected with nearly 1.8 million individuals to provide one-on-one counseling, with an additional 2.6 million contacts via public events, during the 2022 grant year (Congressional Research Service, 2023). Per the ACL, these numbers were achieved with just over 12,500 SHIP associates, half of which are classified as volunteers (Congressional Research Service, 2023). The research shows the SHIP program is a vital resource for helping older adults navigate retirement and there is a need for innovation to help further SHIP's capacity to meet growing demand in the future.

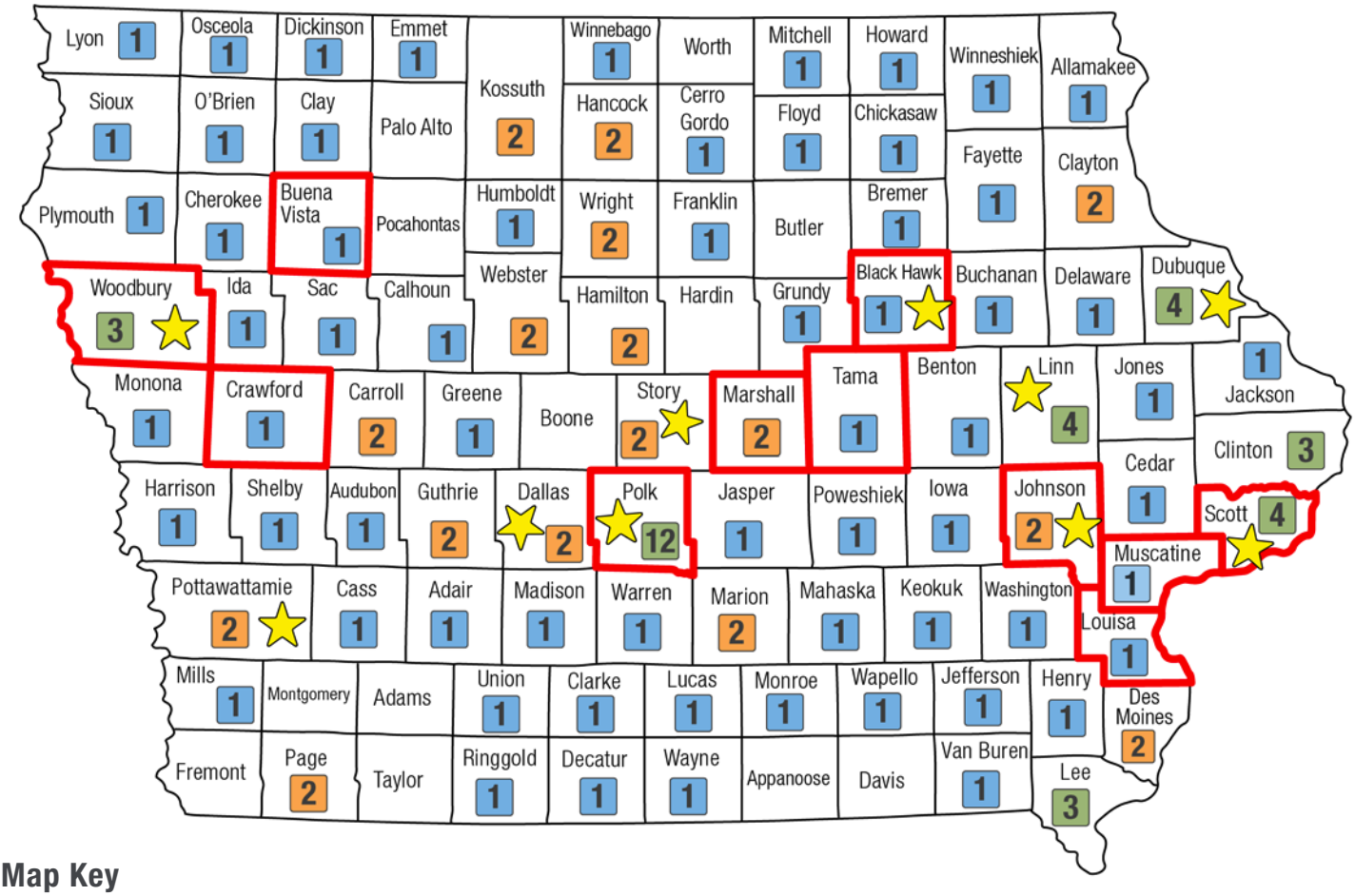
According to Congressional Budget Office projections (2024), Medicare enrollment is expected to increase from 60 million in 2023 to 74 million by 2034. Additionally, Medicare Advantage enrollment is expected to increase to nearly two-thirds market penetration by the year 2034 (Congressional Budget Office, 2024). However, federal funding for the SHIP program has been lower than other similar programs, such as the Marketplace navigator program (Miller, 2022). For the 2023 Open Enrollment Period in the navigator program, the U.S. Department of Health and Human Services invested $98.9 million in grant funding to 59 Navigator organizations, which was comprised of roughly 1,500 existing navigators (U.S. Department of Health and Human Services, 2022). These numbers are much lower than the 2,200 local organizations with 12,500 counselors that support SHIP, yet discretionary funding for SHIP was estimated to be around $55 million for FY2023 (Congressional Research Service, 2023). Without substantial changes in funding,

SHIP offices will likely need to continue operating within the current environment of limited funding and heavy reliance on volunteer counselors, while experiencing significant turnover in volunteers due to the extensive commitment required by the program.

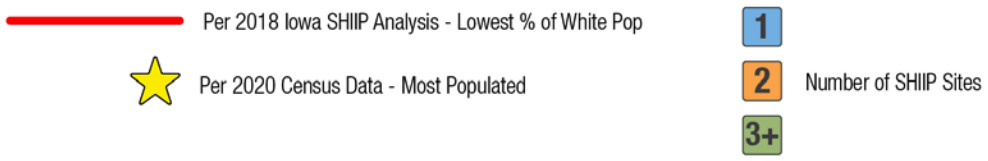
The recommendations shared within this policy report focus on actionable strategies requiring additional funding and resources with the goal of reaching a broader, more diverse population of Medicare beneficiaries. Success within these recommended initiatives would likely result in additional strain on the SHIP counselor workforce as they seek to support a growing number of Medicare beneficiaries. With this in mind, there is a need for more discussion not just on long-term funding for SHIP services, but also counselor recruitment and retainment. Several counselors participating within our research study described the challenging and time-consuming nature of their work as volunteers. Any recommended strategy for expanding the reach and impact of SHIP would also require consideration of how to better support SHIP programs and the counselors that provide outreach and education on Medicare.

Apendix

Iowa SHIIP Site Location Map



Map Key



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