HEALTH EQUITY, URBAN CONGREGATIONS, AND HIP

» Research Report

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Health Equity, Urban Congregations, and HIP: Research Report

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EXECUTIVE SUMMARY

Engaging HIP Members within Their Communities

This study was conducted to engage members of urban Indianapolis communities to chronicle attitudes and experiences regarding the Healthy Indiana Plan (HIP). The research team listened to firsthand users—both HIP members and HIP-eligible people—who can speak to the program's effectiveness in securing health care and promoting wellness for people living in health-challenged neighborhoods.

We conducted our research at two inner-city faith communities, First Baptist Church North Indianapolis and Shepherd Community Center. We explored programs at each congregation and nearby community organizations to understand current use of community assets and potential for community education and support of neighbors' health and wellness. Our ethnographic analysis employed an intentional people-centered participatory approach to give voice to HIP's primary constituency—its members and those eligible but not enrolled—with the goal of improving the program for better health for Indiana residents.

Personal Responsibility and Shared Responsibility

Personal responsibility is a core principle behind HIP. The state's intention is to provide "Hoosiers with opportunities to take charge of their own health care needs."[1] HIP's design differs from other states' Medicaid programs. Members' required payments expect consumer choice from people living near or below the poverty level. HIP's application, documentation, enrollment, payment, and redetermination processes require members to take personal initiative in demonstrating and maintaining eligibility.

The current policy trade-off appears to be this: With taxpayers sharing most of the financial responsibility for HIP, HIP members are largely on their own in taking responsibility for their health, proof of eligibility, enrollment in coverage, and reporting requirements, often without transportation, banking, technology, and other supports that many people take for granted.

With the exception of finances, more is expected of HIP applicants and members compared to Hoosiers with employer-sponsored, federal Marketplace, Medicare, or other Medicaid plans. More is expected in documenting eligibility. More is expected in selecting coverage plans without clear benefits comparisons. More is expected in retaining insurance.

Personal responsibility and shared responsibility work together in health care. Expecting people in the HIP population to find their way alone is harmful to their health and expensive when the costs of delayed or emergency care come due for patients and taxpayers. That is why hospitals, physicians, and mental health providers actively support HIP enrollment by employing financial counselors. Some nonprofit organizations are paying HIP Plus members' monthly premiums to invest in better health for individuals and stewardship of public funds. Some congregations, community centers, and social service agencies are connecting low-income people eligible for HIP to wrap-around services and building relationships to address persistent quality of life issues.

Some members on the more comprehensive HIP Plus plan report significant improvement in their wellness, a welcome sense of belonging in having health insurance, and empowerment in gaining new resources for their health needs as well another complementary services. But this "listening study" heard clearly that the HIP sign-up process is long and confusing, coverage losses occur regularly and inexplicably, and communications are not working for a clientele presenting with diverse issues.

This study's findings and recommendations call on all concerned stakeholders—the Family and Social Services Administration (FSSA), insurers (Managed Care Entities, or MCEs), third-party call center, legislators, health care providers, congregations, and community organizations to step up to the shared responsibility of helping HIP clientele help themselves.

General Findings and Multi-faceted Presentation

This report identifies many points, such as the annual HIP enrollment cycle, mailing address and income requirements, where system design does not sufficiently account for the lived realities of the population of HIP-eligible people. These gaps between design and reality hinder eligible people from securing available health insurance to the cascading detriment of their health, employment, security, and family. Another key finding is that direct personal assistance and relationships with community organizations increase the likelihood of HIP-eligible people's successful enrollment and navigation. We present our results in two formats—this report and two community-partner-produced videos—to accurately convey what we learned and how study participants' input and solutions were harvested.

SUMMARY OF RECOMMENDATIONS

Recommendations that flow from HIP member experiences and insights include:

- Create user-friendly "one stop" HIP Application/Enrollment Tracking System
- Improve FSSA and MCE communications with clear content and multiple communication channels
- Adopt an intentional customer service model for FSSA, DFR offices, call center, and HIP broker
- Shift from quarterly to annual review of income eligibility, with guaranteed one-year of coverage
- Overhaul Medicaid transportation for patient access and security and more flexible payment
- FSSA and MCEs coordinate personal assistance with front-line professionals assisting HIP applicants and members
- FSSA and MCEs create strategic partnerships with government, provider, corporate, community, and faith organizations to expand HIP Plus enrollment and integrate care with holistic services

INTRODUCTION

This community-engaged research study listens to the primary stakeholders of the Healthy Indiana Plan, its members and people eligible for enrollment. Our aim is to share firsthand users' experiences and suggested improvements with state officials, policymakers, insurers, providers, community organizations, congregations, and all of the stakeholders committed to making the Healthy Indiana Plan into our Healthy Indiana Plan.

HIP

In February 2015 Indiana expanded its Medicaid offerings under the Affordable Care Act (ACA). With a Section 1115 Waiver from the federal government, the state took the original Healthy Indiana Plan (HIP), started in 2008, and transformed.[2] HIP covers nearly ten times as many people, contributing to the substantial decrease in Indiana's non-elderly uninsured rate from 16.3% in 2013 to 9.4% in 2016.[3]

HIP includes two different health plans:

HIP PLUS

- A comprehensive medical, pharmacy, vision, and dental benefits package, limits individual members' cost-sharing to a monthly premium of $1 to $20.
- Available to adults age 19 to 64 who have legal proof of citizenship or immigration status, who are not eligible for Medicare or another Medicaid plan, and whose income is 138% or less than the Federal Poverty Level (FPL).

HIP BASIC

- A pared down set of medical and pharmacy benefits with co-pays for each medical visit and prescription, but no monthly premium.
- Restricted to people meeting the same criteria who earn 100% FPL or below.

Both plans use a POWER (Personal Wellness and Responsibility) Account to cover an annual $2,500 deductible.

HIP covers nearly **ten times** as many people, contributing to the substantial decrease in Indiana's non-elderly uninsured rate from **16.3% in 2013 to 9.4% in 2016**

Study Objective

This study takes a deep dive into the experiences of people who are HIP members or who are eligible but not enrolled. The research combines:

1. an evaluation of HIP's program goals of extending subsidized health coverage and promoting personal responsibility, wellness, and empowerment and
2. an inquiry into how two community-facing Indianapolis congregations support health and wellness.

The core research team includes leaders from First Baptist Church North Indianapolis and Shepherd Community Center and IUPUI researchers from the Department of Religious Studies (School of Liberal Arts) and the Department of Visual Communication Design (Herron School of Fine Art and Design). The study opened with conversations with nine navigators and other officials who assist people with HIP enrollment. With participants recruited by the two community partners, we conducted group interviews with 19 congregational and community leaders who help support health and wellness; we interviewed 13 people who were HIP members or HIP-eligible; and we held focus groups with 10 of these interviewees and 28 additional HIP members and HIP-eligible people.[4]“

People-Centered Approach

Our research approach is experiential and narrative not quantitative.

Both community partners also produced a video giving actual voice to the lessons shared by HIP members and some of the health and wellness supports provided by our community partners.[5]

We collected people's stories to hear how HIP is **working** or **not working** in their lives and neighborhoods and to learn where the program is meeting its stated goals and where program changes and community supports might better serve health and wellness.

HIP STORIES

Our study asked people about their health and wellness, health conditions in their neighborhood, and their experiences with health care access and HIP. A few representative stories illustrate some of HIP's successes, shortcomings, and potential.

"So I Said 911"

A 58-year-old man applied for HIP Plus with the assistance of Shepherd Community Center. When he was conditionally approved for HIP in December, Shepherd paid $12 ($1/month) for his year's worth of POWER Account contributions (PAC), but by May his coverage had been cancelled. Despite trouble-shooting by a social worker, paramedic, and financial counselor, the problem remained unclear. Finally, his HIP Plus was reinstated in November.

This man needs maintenance and emergency inhalers for Chronic Obstructive Pulmonary Disease. He reported, "going through the inhalers because they were talking about the pollen, the heat, and everything [last summer]. And with me having little lung problems. But it was hard enough for me to walk from taking the garbage can [30 feet], and I'd come back in and I couldn't breathe. I'd grab the first inhaler that was there, and sometimes it was the one that I was supposed to take once in the morning and once at night, and then two weeks later I'm done with both of them. I'm calling them up, trying to get a refill, and they said no. So I said 911."

From May to November, he called "6, 7" ambulance rides to the emergency department for an inhaler each time: "I got a bill for $2,600 when I didn't have my insurance. They're put into a collection agency right now. I'm like I can't pay that, you're just going to have to wait."

"From May to November, he called "6, 7" ambulance rides to the emergency department for an inhaler each time: "I got a bill for $2,600 when **I didn't have my insurance.**"

"I Could Refer Myself for HIP"

A 55-year-old woman applied for HIP after hearing a Sunday church announcement at First Baptist Church North Indianapolis. While working as a "supportive housing advocate" for a community organization, her role was

> "connecting with the clients that feel like they don't have a voice, and providing the resources for them so that they have what they need to thrive, basically, meeting their needs...Yeah, so to have a plan, a health care plan, that's really important. That's some of the ways that I helped. And, also to remind them that they have choices. If they don't take care of themselves, they can't take care of anyone else."

Having left her job, she was working part-time while pursuing a venture to support women facing mental illness, sexual assault, or addictions: "mental health is real. There are a lot of people in that area, in all areas, that are hopeless. I'm talking about addictions. I'm talking about sexual assault, abuse, lifestyle choices." After leaving her job, she had no health insurance herself. "I've been really busy, and I really don't have any health issues. But God being who he is, I was at church, the announcement was made, speak to Sister Stephanie about the Healthy Indiana Plan for insurance. Let me go see. So I came to see.... I'm one of those people now. That I referred. I could refer myself for HIP."

Shortly after our interview, she applied for HIP Plus with the help of a certified navigator from Covering Kids and Families of Indiana.

"God being who he is, I was at church, the announcement was made, speak to Sister Stephanie about the Healthy Indiana Plan for insurance. Let me go see. So I came to see.... I'm one of those people now. That I referred. I could refer myself for HIP."

"A Lot of the Pulling and Pushing"

A younger woman and college-educated new mother in her mid-20s voiced some of the difficulties interviewees frequently report about navigating the slow, opaque HIP enrollment cycle with multiple parties and inefficient communication. The variety of HIP programs and the technical terminology are challenging even to people familiar with health insurance. In one year she had three different payment levels, with HIP Plus, HIP Maternity (not HIP Basic as she thought) and back to Plus, before losing all HIP coverage:

"Within the last year, I had my son, so I went from HIP Plus and paying a $1 premium to them bumping me down to HIP Basic while I was pregnant. I didn't have a premium at all. Now recently last month, I'm paying $20 [a month] back on HIP Plus. I'm actually in the process of reaching out to them because I'm confused on what that big – that's a big difference as far as paying $1 last year and now here I am paying $20...."

"Right now, it's tight. I'm a single mom, so that $20, I usually use it towards diapers. Versus $1, you don't miss as much. But $20, that's gas or whatever, diapers, wipes."

How was she pursuing her inquiry? "Email, honestly, because when I call, everyone gives me a different answer. They keep basically resending me, so I'll call FSSA, and then they'll send me to [my insurer]. And then [my insurer] will send me back to them. It's just back and forth."

Was she receiving notifications from FSSA (Indiana's Family and Social Services Administration)? Yes, but "a lot of the time they say two different things, or they'll be dated – they could be dated the same day but then they'll say you need to do this [and that]. They're not really clear, at least for me. I always have to call and ask what is this." When asked if she felt supported in getting the health care she needs for herself, for her baby, she answered, "Supported, no. I feel like I have to do a lot of the pulling and pushing."

Interviews like this one leave unanswered questions. The woman's return to a job after her son's birth probably explains the jump in her PAC from $1 to $20 per month. When she lost HIP coverage the month after we met, her income may have exceeded HIP eligibility. A single mother with one child earns too much to receive HIP if she works full-time at $12 an hour. As she notes, paying for health insurance with a child, apartment, car, and other expenses is not viable. As a new mother, she should have received Transitional Medical Assistance for six months following her son's birth, but she never heard of that possibility.

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"HIP Creates Add-ons"

A common thread in many people's stories is the importance of supportive organizations to refer and assist people with HIP enrollment. Nearly everyone we interviewed had applied with assistance from a hospital, clinic, community organization, or navigator. The connections can run in the other direction, too, from having HIP to gaining new wrap-around services.

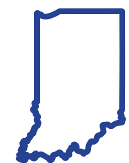
A 62-year-old man explained how HIP Plus opened the door to a life-change. When we met, he was nearing his second anniversary in his apartment after being homeless. HIP Plus covered his mental health and recovery support at Midtown Community Mental Health. There, a counselor, a clinician, and a care coordinator, "would listen. They would listen. Sometimes you need to be heard. We need to know that there's somebody listening."

The case manager heard his needs and challenges, secured housing, and partnered with other community groups for food, furniture, pots and pans. The man describes the transformational connections as "add-ons":

"HIP creates add-ons. Does that make sense? In other words, when you get hooked up with the HIP system, other things become beneficial to you. With Midtown, with [my care coordinator], with the Pour House, with the other places. It creates add-ons. It brings more things to you. And so that would be a really good plus for your study, that it brings more things to the client, to the patient. People think it's just insurance; there's more to HIP than you see."

"People think it's just insurance; **there's more to HIP than you see.**"

BACKGROUND



HIP is now a core health plan offering for low-income Hoosiers, including members of vulnerable populations

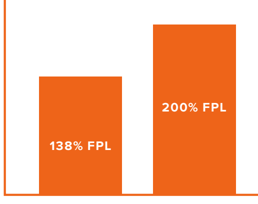
The original HIP was launched in 2008 as a unique Medicaid program using a consumer-driven model to cover 40,000 lower-income Hoosiers (earning up 200% FPL). Consumer-driven health plans aim to put consumers more in charge of spending by combining a health savings account with a high deductible and using payment reforms like eliminating expenses for preventive care while raising cost-sharing for emergency care. Having "skin in the game" is intended to give consumers incentives to ask about prices for health care and health coverage and to allocate their funds toward the health and wellness choices that they judge most valuable. HIP's principal architects, Mitchell Roob, then Secretary of Indiana's Family and Social Services Administration, and Seema Verma, current Director of the federal Centers for Medicare and Medicaid Services, introduced the program as an innovative fusion of values. In their words, "[HIP's] structure melds two themes of American society that typically collide in our healthcare system, rugged individualism and the Judeo Christian ethic. HIP combines these diametrically opposed themes by promoting personal responsibility while providing subsidized health protection to those who can least afford it."[6]

HIP Original vs. HIP

HIP differs in critical ways from the original HIP.

1. HIP increased the number of adults with HIP coverage nearly tenfold. The total of fully-enrolled members rose to 403,075 in January 2018,[7] though it tapered off to 376,392 by December 2018.[8] HIP is now a core health plan offering for low-income Hoosiers, including members of vulnerable populations, such as homeless people, recently incarcerated people, and people living with HIV/AIDS or substance abuse disorder, to name the circumstances of some of the people in this study.

2. Under the ACA, the federal government pays 90% of the expense for HIP members added through the Medicaid expansion. Because the ACA caps income eligibility for this funding at 138% FPL, Indiana cuts off HIP eligibility at 138% FPL, lower than the 200% FPL cut-off for those fortunate 40,000 people approved for the original HIP.



Indiana cuts off HIP eligibility at 138% FPL, lower than the 200% FPL cut-off for those fortunate 40,000 people approved for the original HIP

3. The consumer-driven features of the original HIP are diminished in HIP.

- Although the annual deductible jumped to $2,500, HIP Plus members' PAC are capped at 2% of income (now paid on a sliding scale of $1, $5, $10, $15, or $20 per month). With the state funding 91-99% of Power Accounts for HIP Plus members and 100% for HIP Basic members, members are significantly shielded from spending their "own" health care dollars.

- In line with the ACA, HIP has no annual cap on preventive services (limited to $500 under the original HIP), further reducing members' incentives to request price transparency from providers and prioritize cost-effective health care services as judged by the consumer.

- The original HIP allowed members to rollover any unspent PAC in their POWER Accounts to offset future PAC, provided they completed required wellness visits. HIP allows this rollover regardless and doubles it with completed wellness visits, but the rollover potential is lower because PAC are on average lower under HIP.

4. The final major change is HIP's two-tiered system of health coverage. HIP Plus, the top-tier benefits package, is reserved for eligible members who pay their monthly PAC, which can be paid as a lump sum for up to one year.

By program design, every applicant who is conditionally approved starts at the HIP Plus level, though they will not receive the Plus benefits unless they pay their first month's PAC to the insurer (Managed Care Entity, or MCE) who provides the coverage and manages their POWER Account. When members do not pay, or stop paying, their PAC, they are not enrolled, or are disenrolled, from HIP Plus. If their income is 100% FPL or below, their coverage drops to HIP Basic. If their income is between 138% and 100% FPL, they lose coverage and are locked out of reapplying for six months.

"Everyone Starts on HIP Plus"

A manager of financial counselors for a hospital's primary care network observed, "Everyone starts on HIP Plus." HIP Plus is the preferred plan with more features of the original HIP. Despite this default of starting on HIP Plus, the data demonstrate that HIP's potential has not been realized.

- As reported by the Kaiser Family Foundation, "more than half (55%) of all of those eligible to pay [PAC] premiums under HIP during the first two years of implementation failed to do so." Of this group, 287,000 were assigned to HIP Basic. Another 59,550 earned above 100% FPL and were never enrolled or were disenrolled from HIP Plus.[9]

- At the end of the program's third year (Jan. 2018), 65.8% of HIP members were enrolled in HIP Plus and 34.2% in HIP Basic. Among African Americans, however, only 51.8% were enrolled in the preferred HIP Plus compared to 48.2% in HIP Basic. African Americans are most affected by this racial disparity in HIP Plus enrollment, which remains stubbornly persistent from Demonstration Year 1, when the figures were 49.5% enrolled in HIP Plus and 50.5% in HIP Basic.[10]

- According to the state's *Annual Report for Demonstration Year 3*, 24% of the people who had HIP benefits or were approved between Feb. 2017 to Jan. 2018 no longer had HIP coverage at the end of this period.[11]

HIP Plus retains the original HIP goals of extending subsidized health coverage and promoting personal responsibility and wellness through a consumer-driven model. HIP Plus offers comprehensive benefits and eliminates the financial barrier of co-pays, in exchange for the member's required PAC. HIP Plus is the entry point for every applicant who is conditionally-approved for the program.

"Everyone starts on HIP Plus." How then account for the large number of eligible Hoosiers who have HIP Basic or no coverage at all? Our study explores this question (and many others) with the goals of hearing people's experiences with health, health care access, and HIP, identifying HIP's successes, barriers, and unrealized potential, and recommending program improvements and community strategies so that HIP can truly become our state's Healthy Indiana Plan.

55%

More than half of all those eligible to pay [PAC] premiums under HIP during the first 2 years of implementation failed to do so

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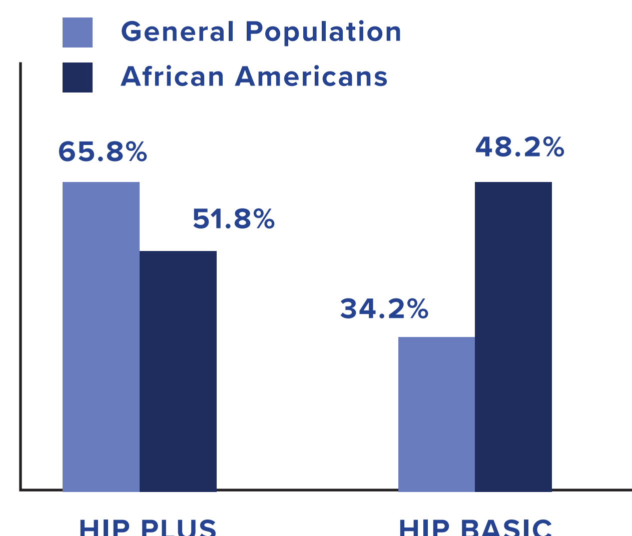


PROJECT PARTNERS

This study is a community-university partnership. Our interviews sought to gather the lived experiences of HIP-members and HIP-eligible people and collect local knowledge about health assets and barriers in two different study neighborhoods. Our focus groups asked HIP-members and HIP-eligible people to recommend solutions to common challenges with HIP. The study worked within and through the two community partners' established relationships and trust to develop a richer snapshot of neighborhood conditions and people's lives than would be possible without community-based participatory research.

The two community partners operate on different models, reflected in our recruitment at each site. All of the First Baptist Church North Indianapolis interviewees are congregants who do not currently live in the neighborhood. Focus groups drew in congregants and neighbors, recruited partly through nearby churches and a community center. All of the Shepherd Community Center interviewees live in the neighborhood or nearby homeless shelters, and many attend Shepherd's Celebration Church. Focus groups drew from these locations, too.

First Baptist Church North Indianapolis

First Baptist Church North Indianapolis (https://firstbaptistnorth.org) is a church that discerns how their ministry extends out into the community and then develops programs and finds volunteers and resources to run them. Located near W. 28th St. and Martin Luther King, Jr. Blvd., First Baptist Church North Indianapolis has ministered in their neighborhood for 134 years, the oldest social service organization in this northwest neighborhood. Rev. Dr. Ivan Douglas Hicks, co-Principal Investigator, recently completed his twentieth year as senior pastor. Church administrators, Stephanie Patterson and George Armstrong, coordinated recruitment and participant engagement. Here is a sample of the programs First Baptist Church North Indianapolis has sponsored in recent years related to health and wellness for congregants and neighbors: Tuesday tutoring and dinner for School 42 children, Thursday hot lunches for neighbors, First Sunday Brotherhood breakfasts for neighbors, week-long summer camp, summer Friday night youth gatherings and parents night-off for neighbors, a healthy living class, Lafiya Wellness Ministry information and screening programs, classes for parents with autistic children, a food pantry, clothing closet, as well as an entrepreneurial-development program, The Grindery, and a new Resource Store they are building with neighborhood partners, Holy Angels Catholic Church and School 42. The church's weekly services and teaching classes are also key components of their commitment to holistic wellness.

First Baptist Church North Indianapolis is located in the Near Northwest in a predominately African-American (89%) neighborhood. ***Census tract data shows the following demographic comparisons to Marion County:***[12]

- 41% of adults living in poverty (2+ times county average)
- 41% vacant houses (3 times county average)
- 50% of insured residents on Medicaid (2 times county average)
- 34% of occupied housing units with no vehicle available (3 times county average)
- 48% of households receiving SNAP (2.5 times county average)

Data from the Indianapolis Metropolitan Police Departments on this census tract reports:

- 700% higher murder rate, 800% higher non-fatal shootings, and 70% higher drug overdoses than county averages
- 90% higher EMS call rate for mental health than county average

Shepherd Community Center

Shepherd Community Center (https://www.shepherdcommunity.org) is a community center linked to the Shepherd Community Church of the Nazarene. The Shepherd Community Church has 3 services meeting on Sundays. Located near Sherman Dr. on E. Washington St., Shepherd Community Center has served this eastside neighborhood for 35 years. Their approach to breaking the cycle of poverty provides a Continuum of Care of hope and help for neighborhood children, teens, and their parents to develop a holistic set of capacities for wellness. Andrew Green, Assistant Executive Director with 13 years at Shepherd, was the co-Principal Investigator there. Here is a sample of the programs Shepherd has sponsored in recent years supporting health and wellness for more than 500 families (1,000+ individuals): a pre-school and K-5 school, adult education, ESL, financial literacy, job training, and cooking classes, new parent support, Saturday gatherings and food pantry, and, up until recently, a health clinic. Shepherd works with several community partners on the 46201 Project supporting housing, health, hunger, and hope. They fund and collaborate with Eskenazi Health and the Indianapolis Metropolitan Police Department on the Shalom Project, described in this report.

Shepherd Community Center is located in the Christian Park area in a mixed Caucasian (48%), African-American (37%), and Latino (12%) U.S. census tract.[13] ***Shepherd's data on their immediate neighborhood finds:***

- 37% of people living below the Federal Poverty Level (2 times Marion County average), and a median household income per capita only in the 3rd percentile
- 61% of people living in poverty in some areas
- 35% vacant houses (over 2 times county average), and only 30% of people own their homes in an area with a population density in Indiana's 99th percentile
- 200% higher murder rate, 400% higher non-fatal shootings, and 340% higher drug overdoses than county averages

Data from the larger U.S. census tract reports:

- 37% of insured residents on Medicaid (1.5 times county average)
- 21% of occupied housing units with no vehicle available (2 times county average)
- 29% of households receiving SNAP (1.5 times county average)

IUPUI Partners

The university partners on this study are from IUPUI's School of Liberal Arts, Herron School of Art and Design and IU School of Medicine Clinical and Translational Sciences Institute. Dr. David Craig, Professor of Religious Studies, and Principal Investigator, used his qualitative interview experience and policy expertise on health care reform.[14] Maria Meschi, Master's candidate in Visual Design Research, led and facilitated the participatory design focus groups and analyzed the data under the advising and mentoring of Pamela Napier, Associate Professor, Visual Communication Design. Student interns, Matthew Wilcox and Fiona Schicho, re-coded and analyzed all of the interviews, and Payton Fischer compiled neighborhood data.

METHODS

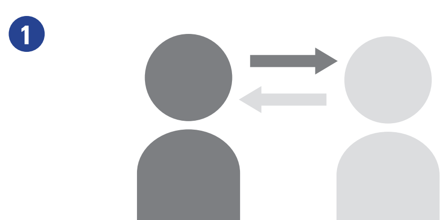
Community-Based Participatory Research

This community-academic partnership began with collaborative development of the research design. The study had two main research goals:

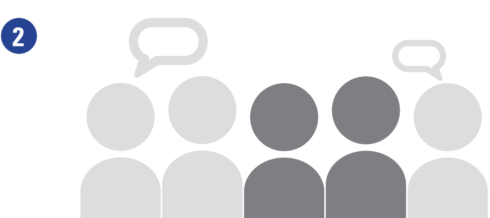
1. Assess HIP's efficacy and report community-identified breakdowns between HIP benefits and requirements and the lived realities of health seekers in health-challenged neighborhoods.

2. Examine two Indianapolis congregations' healthy community programs as alternative supports for promoting health and wellness and achieving HIP's values.

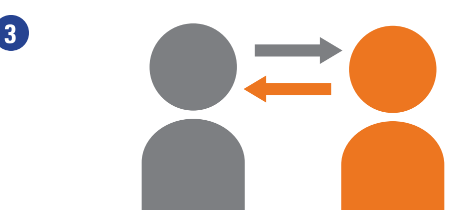
The research team used a combination of semi-structured interviews and people-centered design focus groups to engage three constituencies.



First, Dr. David Craig conducted "fact-finding" interviews with nine people who help enroll members in HIP and navigate its benefits, including certified navigators, financial counselors, recovery coaches, a community health worker, and a legal advocate. This fact-finding helped identify existing resources and persistent challenges for HIP members, which the research team used in designing interviews and focus groups.



Second, each community partner invited leaders of their health and wellness programs and leaders from local partner organizations to two group interviews at each site. Conducted by Dr. Ivan Douglas Hicks and Dr. Craig at First Baptist Church North Indianapolis and by Andrew Green and Dr. Craig at Shepherd, the interviews used a "team" approach, asking 19 participants to share and compare their local knowledge of health assets and barriers in the study neighborhoods, each partners' health and wellness programs and priorities, and the participants' awareness and assessment of HIP.



Third, each community partner helped recruit the study's primary constituency, HIP members or people who are eligible but not enrolled. These participants could be congregants or residents from the study neighborhoods. Efforts were made to ensure that the demographics of these participants matched the racial, ethnic, and gender diversity of the two neighborhoods. The Latino presence in the Shepherd Community Center neighborhood is not adequately reflected, however, largely because of HIP's requirement that members have legal proof of citizenship or immigration status. Recruitment occurred after congregational services, through announcements at other neighborhood organizations, and word-of-mouth snowballing. Dr. Craig conducted one-hour interviews with a total of 15 congregants and neighbors (two interviewees were not HIP-eligible because they had the Medicaid plan, Hoosier Care Connect; they are not included in our results).

Led by Maria Meschi and Pamela Napier, the research team held six 90-minute people-centered design focus groups, three at each site.

The first two sessions brought some of the interviewees together as a "team" of knowledgable participants to share and compare their assessment of HIP's successes and challenges. These "neighbor teams" finalized the HIP Process Map presented at the end of the Methods section and used by participants in the final four focus groups.

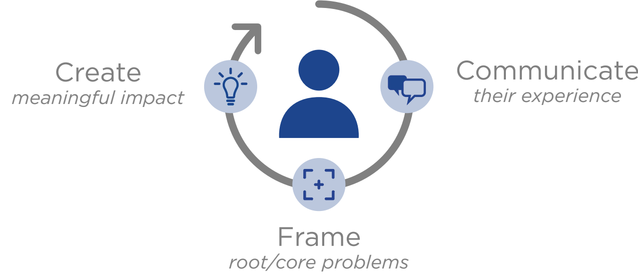
The final focus groups expanded the study to an additional 28 people who were HIP members or HIP-eligible. Using their experience and knowledge, they proposed solutions to address community-identified breakdowns between HIP benefits and requirements and the lived realities of health seekers in health-challenged neighborhoods.

Although unintended, we acknowledge a selection bias in our recruitment. The 13 participants in our initial one-hour interviews were mostly well-known to our two community partners. More connected to our partners' support networks, they were more connected to HIP. Only two of the initial interviewees had experience with HIP Basic compared to ten who had experience with HIP Plus. Only one person who was eligible for HIP had never been on it because she was only recently eligible. The last four focus groups drew a more representative mix of people on HIP Plus, HIP Basic, and HIP-eligible but unenrolled. In short, our initial interviewees have likely had relatively better experiences with HIP than the broader population of HIP-eligible people.

People-Centered Approach & Design Facilitation

Community participation and voice are essential to this research. At every step, the community research leads collaborated on the research design and questions. The "leader teams" collectively shared their deliberation and action regarding how to use their own and other local health assets to support neighbors' health and wellness and develop their capacities. Participatory knowledge was most critical to the people-centered design focus groups. People-Centered Design is an approach and methodology to create relevant and appropriate solutions through a focus on designing with people, rather than for people. This approach utilizes Design Thinking and Participatory Design Research methods to empower the people who ultimately use a product, service, or system to collaboratively create positive impact and innovation. It is an inclusive way to help people: communicate their experiences for a deep understanding of the root of problems and then collaboratively create meaningful impact through solutions developed by the very people who will use and implement them.

Design Facilitation is a distinctive capacity for driving and leading participatory, people-centered design. Focus groups were led by Design Facilitators, Maria Meschi and Pamela Napier, skilled in collaborative problem-solving processes—using creative methods and tools—enabling people to express, share, ideate, prototype, and evaluate throughout the process.



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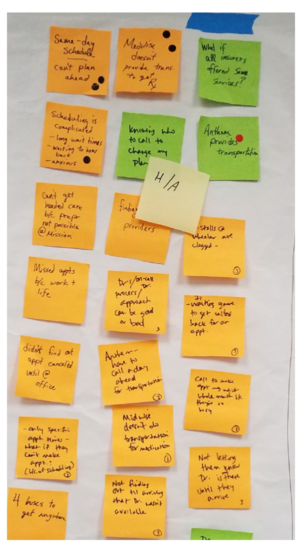
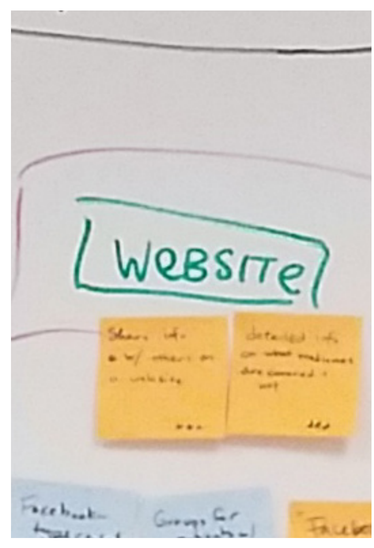
Data Collection and Analysis

The interviews with the leader teams and with the initial 13 HIP-member/HIP-eligible people were audio-recorded and transcribed. Dr. Craig coded the transcripts into broad themes and shared the results with the community research leads. Two student interns experienced in qualitative community-based research re-coded the transcripts to discern more fine-grained patterns and the frequency and intensity of repeat observations and issues.

Results from the six focus groups were collected visually through participants' use of stickie-notes, vote-stickers, and oversize post-its. Facilitators recorded verbal contributions using the same means. Results were photographed and retained for later analysis. One of the key research outcomes is the HIP Process Map created by Maria Meschi and finalized in the Neighbor Team Focus Groups (see below).

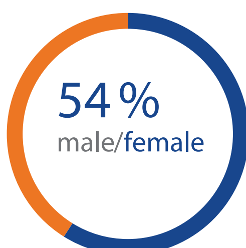
The research team examined the results from the four HIP Focus Groups using three framed challenges as an initial framework. From this data, three primary solution spaces emerged for the major challenges faced by HIP-users: improved communication, intentional partnerships with other organizations, and a personal assistance program. Study Findings and Recommendations are outlined in the next two sections.

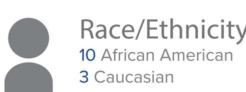




HIP INTERVIEWEES

13
total participants





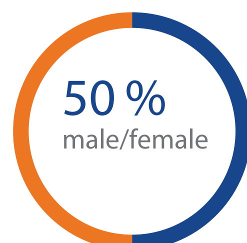
Race/Ethnicity
10 African American
3 Caucasian

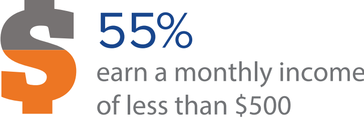
Age
19-29: 2 40-49: 2 60-64: 2
30-39: 1 50-59: 6

PARTICIPATORY DESIGN SESSION PARTICIPANTS

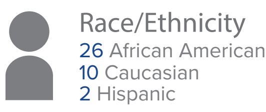
38
total participants

Age
19-29: 2 40-49: 10 60-64: 9
30-39: 3 50-59: 15



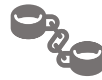


55%
earn a monthly income of less than $500



Race/Ethnicity
26 African American
10 Caucasian
2 Hispanic

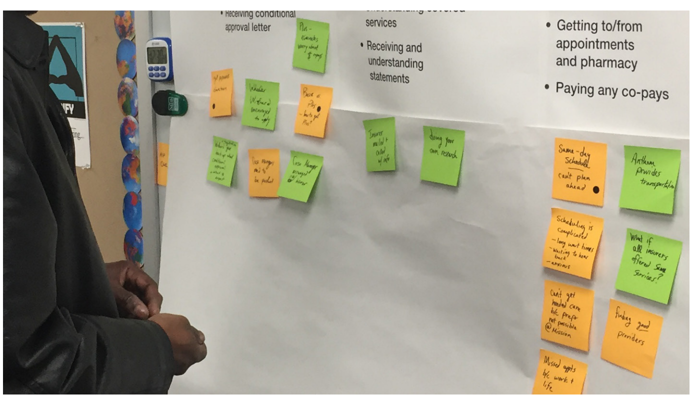
14
have experienced homelessness

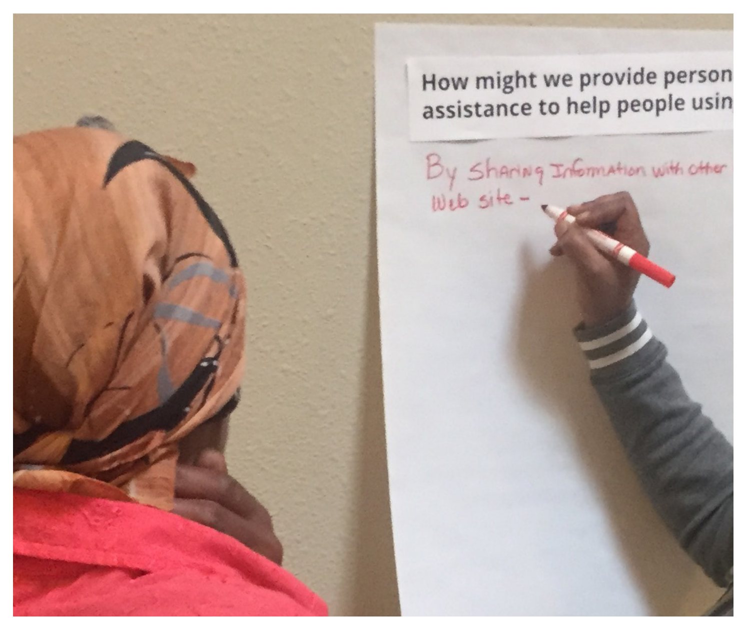


6
have been incarcerated

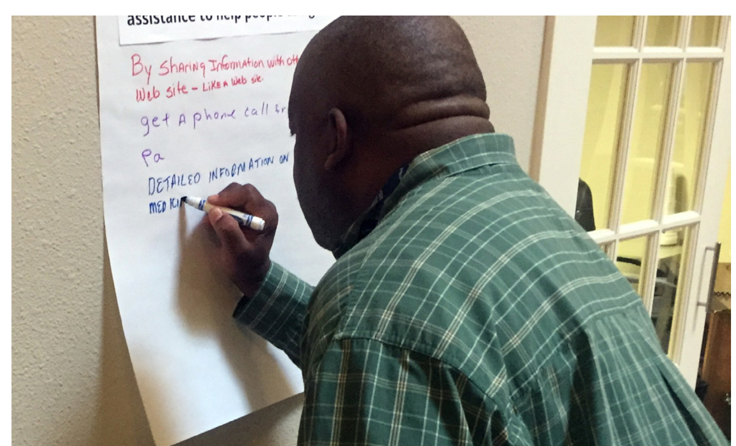
6
have been affected by substance abuse

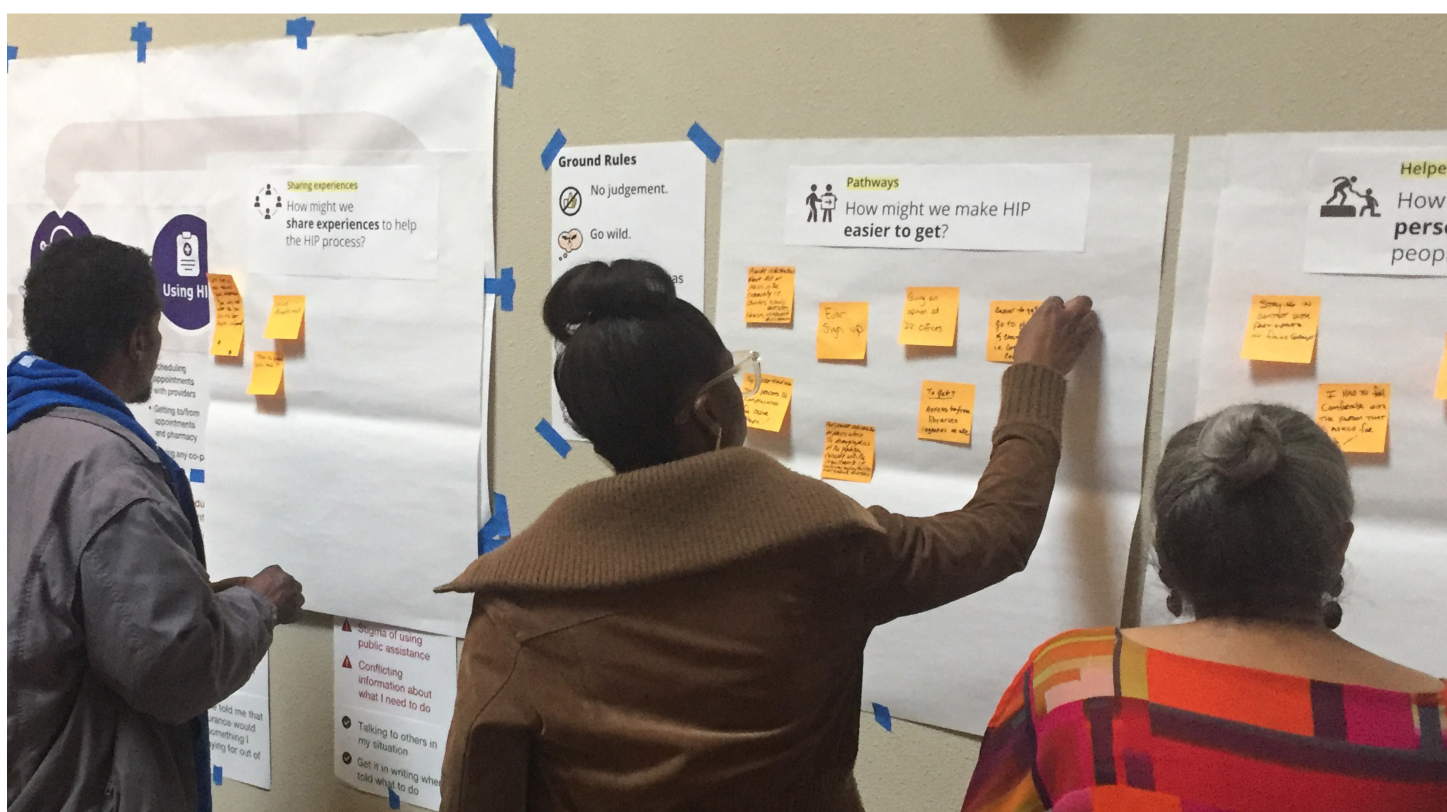
3
are living with HIV/AIDS


Getting to/from appointments and pharmacy
Paying any co-pays
Receiving and understanding statements


By Sharing Information with other Web site -

Getting HIP
Connecting to Insurer
Using HIP
Completing application
Receiving enrollment information
Understanding covered services
Receiving and understanding statements
Paying any co-pays


get A phone call
DETAILED INFORMATION ON


Sharing experiences
How might we share experiences to help the HIP process?
Ground Rules
No judgement.
Go wild.
Pathways
How might we make HIP easier to get?
Using HIP
Conflicting information about what I need to do
Talking to others in my situation

OUTCOME: AMENDED HIP PROCESS MAP

Following the Neighbor Team Sessions, the research team synthesized the common barriers and supports into an amended process map.

- Completing application
- Submitting documents
- Receiving conditional approval letter

Not knowing what my options are

Getting the documents requested

Waiting / not knowing what's happening

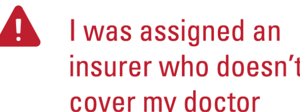
Having someone to complete and submit my application

Having someone who knows the process tell me what to do

- Receiving enrollment information
- Understanding covered services
- Receiving and understanding statements

I was assigned an insurer who doesn't cover my doctor

How do I find a new provider who is "in network"?



Paying premiums

Doing research to understand my new plan

- Scheduling appointments with providers
- Getting to/from appointments and pharmacy
- Paying any co-pays

Scheduling appointments

Unreliable or expensive transportation

My appointment or coverage changed and no one told me until I was at the office

Some insurers cover transportation

Someone told me that my insurance would cover something I was paying for out of pocket

- Paying monthly contributions (if HIP Plus)
- Responding to letters from FSSA
- Reporting work requirement
- Recertifying

New work requirement - I don't know if I'm exempt

My income is too high for HIP, but not enough to cover my needs

Stigma of using public assistance

Conflicting information about what I need to do

Talking to others in my situation

Get it in writing when told what to do

FINDINGS: CURRENT STATE OF HIP

The Advantages of HIP Plus

Finding 1: HIP Plus Benefits Are Rated Highly

Interviewees who have HIP Plus generally rated their benefits highly for: 1) the wide array of covered services and 2) no out-of-pocket costs. Members appreciate HIP Plus by comparison with not having health insurance. HIP Plus offers health protection and security that members could not otherwise afford.

> **"Thank goodness we do have the HIP, but I went years without, I couldn't afford insurance....** I did not go get help. That's part of why I have a lot of these [chronic] issues because I would never ever go to the doctor or the dentist because I could not afford it."

In their years without coverage, interviewees reported avoiding using healthcare or finding other ways to deal with medical issues, such as waiting until there was an emergency or, in some cases, self-medicating through alcohol and drugs. "Thank goodness we do have the HIP, but I went years without, I couldn't afford insurance.... I did not go get help. That's part of why I have a lot of these [chronic] issues because I would never ever go to the doctor or the dentist because I could not afford it." (Interviewee 13)

HIP Plus has different levels of coverage. For example, the more generous State HIP Plus program adds benefits for medically-frail individuals, including improved transportation. As one member noted, "To be a good insurance, people need to know that they don't have to worry about that. I don't have to worry about my insurance. I don't have to worry about how to get to the doctor to get my medication. I'm going to pay for my medications." (Interviewee 8) Not all HIP Plus plans offer the same level of support and security.

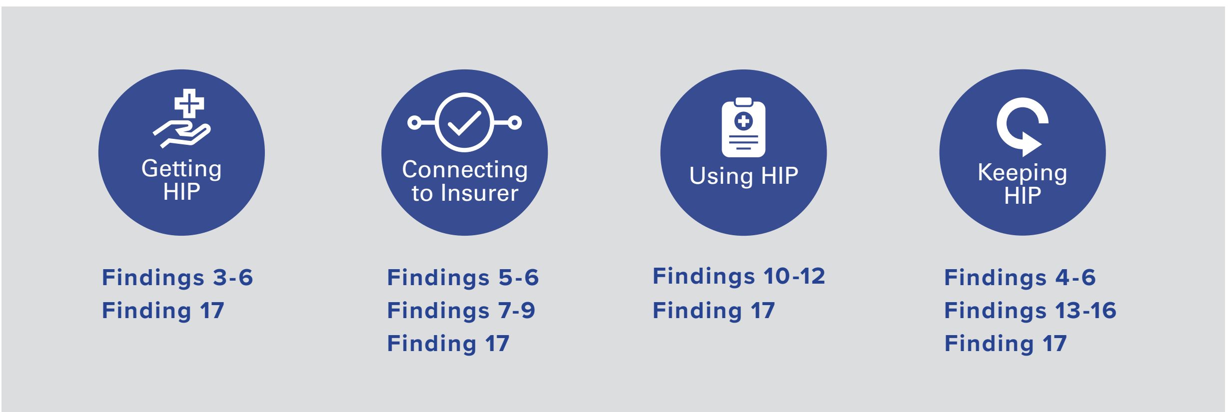
Finding 2: HIP Plus Can Transform Health Care Access for Wellness

HIP Plus' comprehensive coverage and no co-pays help members establish relationships with primary care and/or mental health providers. By securing access to primary care visits and care integration, HIP Plus has the potential to redirect health-seekers from acute and emergency care toward routine wellness and chronic disease management. HIP Plus is a key tool for the state as we all try to adapt to a culture of wellness.One woman confirmed the transformative potential of HIP Plus in describing her own shift toward wellness.

> "Now, I haven't been through emergencies in a while, a nice little time, because I go to the doctor all the time. He makes sure you've got to do this, Ms. P, you've got to do that, **I want you to live, I want you to keep coming back. "**

"Last year [on HIP-Plus], I went to the doctor from the bottom of my feet to the middle of my midsection, all the way to the top of my head to my vision, I was at a doctor... Since Obama made us start going to the doctor, that's when I started going to the doctor because I didn't want to go through emergencies [like my stroke]. Now, I haven't been through emergencies in a while, a nice little time, because I go to the doctor all the time. He makes sure you've got to do this, Ms. P, you've got to do that, I want you to live, I want you to keep coming back. I'm like, okay, okay, okay." (Interviewee 1)

HOW FINDINGS RELATE TO AMENDED HIP PROCESS MAP



Although most of the HIP Plus members in our interviews had regular primary care providers and expressed considerable satisfaction with their coverage, focus group participants reported lower levels of satisfaction. Upon learning that other members have case managers, several people asked how they could get a case manager to assist them with integrated care and mental health services.

HIP Operations

Health insurance is complicated, but even people familiar with employer-sponsored health plans find HIP harder to understand. As one interviewee put it,

"employer insurance is smoother, you're signed up more quickly.... It was cut and dry. I understood it. I knew what was going to be taken out of my paycheck. Versus HIP, the coverage for the price really isn't bad. It's just understanding everything that's in that. If you've never been on [HIP] before and this is your first time signing up, then it can be really confusing. A lot of phone calls, back-to-back phone calls, just a little bit more work than I feel like we should have to do." (Interviewee 7)

The next set of Findings about HIP Operations build on the HIP Process Map on pages 18-19. Developed by the research team, the graphic highlights:

1) the four main steps in the annual HIP cycle: Getting HIP, Connecting to Insurer, Using HIP, and Keeping HIP,

2) the different entities that approve (FSSA), assign (third-party broker), administer (MCEs), and field questions (call center) about HIP, and

3) the "helps" and "hindrances" that interviewees and focus group participants identified as supports or barriers in their experiences with HIP.

In this section, we focus on the barriers that members identified before turning to helpful supports.

Finding 3: Slow Application-to-Enrollment Timeline Frustrates Coverage Goals

HIP has a significant time-lag from the date a person applies to the date of actual enrollment in health coverage. FSSA has 45 days to process a complete application, get a member assigned to an insurer (MCE), and send the applicant a conditional approval letter. Approval is only conditional because the member must pay the first month's PAC before HIP Plus benefits start the next month. In other words, it can take two months to get HIP Plus under the best circumstances.

If a conditionally-approved applicant does not pay the PAC within 60 days of notification and if he or she has an income 100% FPL or below, then HIP Basic benefits will start the month following the end of the 60-day PAC-payment window. Conditionally-approved applicants cannot signal their desire to be on HIP Basic sooner; they default to HIP Basic because of non-payment. All told, it can take four months to get HIP Basic.

This application-to-enrollment timeline is not a bureaucratic back-log. It is a built-in feature of the 2015 HIP waiver intended to serve two goals:

1) nudge conditionally-approved applicants to join the preferred HIP Plus by paying their PAC, and

2) deter HIP members from starting and stopping coverage as they need it.[15]

In theory, the application-to-enrollment timeline has the laudable aim of motivating people to pay into the comprehensive HIP Plus plan and also maintain continuous health coverage. In practice, interviewees report significant frustration and confusion caused by enrollment delays.

FSSA data reports that processing time for approvals is typically faster than 45 days, averaging 21 to 24 days.[16] Even current waits create uncertainty, during which time, applicants may

- restart their application, which terminates their previous application(s), restarts the review, and further delays the process,
- forget critical education they learned while applying, such as the need to pay their PAC when contacted by their assigned MCE, or
- lose track of their application entirely.

A housing advocate who supports homeless people put the lengthy approval-to-enrollment process in perspective:

"When I think about the weather we had, and [my clients are] sleeping under a bridge, 45 days is a long time. Now, I can understand why some of them are like, you know what, it's too long. I'm just going to go to the emergency room when I'm hurt, when I'm ill, and I'll just deal with the bill, whatever then, because...there's so much going on in a 45-day period for a homeless person.... if you are, for instance, dealing with mental health, if you don't have the capacity to go through this complex maze of this process, then you're out." (Leader Group 3)

FAST TRACK PRE-PAYMENTS

HIP includes the option of paying a $10 Fast Track pre-payment at the time of application. The payment is meant to expedite application approval and, more importantly, make HIP Plus coverage retroactive to the date of application. The Fast Track is also an initial deposit on one's PAC for the first month of coverage (or more if PACs are less than $10 per month).

One of our best-informed interviewees reported disappointment with her own experience with Fast Track payments. "I was trying to get Fast Tracked before the end of the month. I'm like it's not even working. And the girl at the office, the Aid Office, she told me it doesn't even work." (Interviewee 6)

According to several financial counselors we interviewed, Fast Track payments are a vital tool that hospitals use to help uncovered patients be able to pay for emergency and inpatient care. Hospitals must first qualify patients for "presumptive eligibility" by midnight of the day arrive. Then if Fast-Tracked applicants pay their full PAC within 60 days, their hospital bills will be covered. According to a community health worker, hospital patients may have too high of an income for HIP when they first present. After illness, treatment, and recovery, they may have lost their job and become eligible, at which point Fast Track payments may come too late. Applicants have 30 days to make a Fast Track payment, which is why follow-up in-home visits can be crucial for patients living on the edge, both for health and financial reasons.

Finding 4: Document Expectations and Processing Can Be Prohibitive

HIP's document expectations and processing are major barriers to enrollment and coverage. Documents must be mailed or faxed to FSSA or taken a Division of Family Resources Office. Many interviewees were frustrated that there is no online submission system for uploading documents. They stressed the importance of hand-delivery to get documents time-stamped to have proof of submission if—many said when—their documents are lost or not processed on time.

"I had HIP back in 2017. Then, there was something and they disconnected it. I turned in new paperwork, but they said they didn't get something. And when you're working, you

can't keep going down there. It took a minute, and I got it, so I reapplied, got all of the stuff into them again and then I got [HIP] back. They claimed they didn't have some document or something. I don't know, because the amount that I made at my last job was more than I made at the new job, so it couldn't have been income. But they're always saying that they need this document, or that they mailed you this document." (Interviewee 2)

The challenges of providing documents, including a birth certificate, social security card, envelop with home address, paystubs, and more, can be prohibitive for vulnerable Hoosiers. The housing advocate for homeless clients explained, "There's one agency in Indianapolis that helps people get birth certificates from out of town. They do it every Monday. They see 10 people in the morning. If there's 50 people in line, they've only got the money to help 10. You have to be in line at 5 AM. Their doors open at 7. You have to wait in line for two hours to hopefully get your birth certificate." (Leader Group 3)

Documentation requirements extend beyond application. Like other insurance, HIP has to be renewed annually, but it is not automatic. For their annual redetermination, HIP members must submit information on income, home address, household membership, and other updates to keep their benefits. Members must submit documents more frequently if they have job changes and other status updates. (see Finding 15)

A particular area of concern is documenting job changes. Members are responsible for getting their former employer to certify that they left or lost a job, a hurdle made more difficult if the member was fired, departed under bad terms, filed a complaint against the employer, was a temporary worker, or if the business no longer exists. One interviewee reported filing notice that his wife had left her job two years prior. But the job remained in FSSA's system: "for some reason, they still have on the paperwork that she's still employed. She hasn't been employed in almost two years because we just had a new child..... I know that most agencies such as social security or the food stamp office, most of them are tied in together so that information should already be available to them. I shouldn't have to keep doing this." (Interviewee 3)

Finding 5: Shifting Program Responsibilities Create Support Gaps

HIP requires coordination among three different entities: 1) FSSA, 2) MCEs, and 3) Maximus, the contracted third-party HIP broker and call center operator. The typical application process, for example, involves a hand-off from FSSA to an MCE often via the HIP broker who assigns applicants to an MCE if they have not chosen one on the application. (see Finding 7). From the perspective of our interviewees, these transfers from one responsible entity to the next often do not run smoothly.

> Members do not experience these transfers as seamless coordination; they experience them as passing the buck from one responsible entity to the next, with members falling through the cracks.

Financial counselors report that conditionally-approved HIP applicants sometimes misread their conditional approval letters as full enrollment. They assume they have coverage and take no action when their MCE sends them their plan information and their first POWER Account statement and PAC invoice. In the best-case scenario, they will eventually move onto HIP Basic, but months later. If their income is between 138% and 100% FPL, they will be locked out of coverage for six months before they can re-apply.

Another problem area cited by interviewees is poor coordination between FSSA and the call center. Apparently, the call center is limited to fielding members' questions and referring but not resolving them. FSSA employees are the real decision-makers with the power to resolve members' appeals or trouble-shoot problems. Experienced navigators and financial counselors report basically ignoring the call center and seeking direct contact with FSSA to solve their clients' issues.

Because program responsibilities shift among these different entities, HIP applicants and members are left to navigate the steps of Getting HIP, Connecting with Insurer, and

Keeping HIP with little clarity about who is responsible for assisting them along the way. Members do not experience these transfers as seamless coordination; they experience them as passing the buck from one responsible entity to the next, with members falling through the cracks.

One successful HIP-user described her navigation strategy as relentless phone calls:

"You have to call. To call to check up, because you hear one thing over the phone, and they give you this interview over the phone, this little short 2-5 minute interview over the phone, and it's like you qualify for this, and it's just got to go over to the state. And then it gets over to the state and it gets kicked out for some reason. Well, wait, what happened? I'm looking through my check stubs, and I know there's two different income levels for food stamps, for medical. I'm like, yeah, I'm here, I'm there. You just have to go back and do your due diligence.... So you have to make sure that you call about everything." (Interviewee 6)

According to interviewees, back-to-back phone calls are par for the course when trying to navigate HIP on one's own. That is why interviewees and focus group participants stress the importance of three personal helps:

1) someone who can complete and submit an application on your behalf,

2) someone who can clearly explain the full application-to-enrollment process, and

3) someone you can authorize to receive duplicate notifications by mail and advocate with FSSA.

We discuss the importance of the person-to-person support offered by certified navigators, financial counselors, community health workers, and others below.

Finding 6: No Easy Online System for Tracking Application, Documents, and Coverage Status

Given these challenges of a long enrollment timeline, documentation expectations and problems, and multiple entities with shifting responsibilities, interviewees expressed frustration that FSSA does not provide an online system

FSSA should develop a system where members can track applications, documentation, coverage, and required updates like annual redetermination.

where HIP applicants and members could easily track the progress of an application, the processing of documents, any requests for new documents, and the status of their coverage. Providers and pharmacies are able to track members' coverage status, and interviewees frequently learn about coverage lapses at the doctor's office or drug store.

Several navigators and financial counselors who help enroll HIP applicants proposed that FSSA should develop a system where members can track applications, documentation, coverage, and required updates like annual redetermination. The resourceful interviewee from above reported a call-in system for tracking applications. "You can call the FSSA, and they have where you can check the status of your application. You put in your last four [Social Security digits], and they'll tell you. It's like an automated system. Or you can get a live person. I've got a live person before and found out that my documents are there, they just haven't entered them into the system yet, and so they'll just go in and do it at that moment." (Interviewee 6) This call-in resource is not well-known to study participants. This member's experience with stalled-out document processing underscores the need for a readily-accessible tracking system.

Finding 7: Affordability Hinders HIP Plus Membership

< 50% FPL

Indiana is unique among the fifty states in requiring Medicaid members earning below 50% FPL to pay premiums (or PAC).[17] Without making these monthly payments to their MCE, Hoosiers cannot receive the comprehensive benefits of HIP Plus or avoid co-pays. Even the $12 in annual PAC for the lowest-income HIP

"If you're being completely honest, how are you supposed to get $12 to pay? I mean honestly. **They're teaching you to go beg, borrow, and steal.**"

Plus members (0% to 23% FPL) is a deterrent to HIP Plus membership. Having experienced this situation herself, one of our interviewees observed, "If you're not working, and they tell you you have to pay $12 a year, but you haven't got disability and you're not working at all, you have no funds, period. If you're being completely honest, how are you supposed to get $12 to pay? I mean honestly. They're teaching you to go beg, borrow, and steal." (Interviewee 13)

A significant number of study participants work seasonal or temporary jobs. The boom-and-bust nature of their work means their earnings may rise above their monthly average for several months before dropping to zero. HIP-eligibility and PAC amounts are based on quarterly income reviews, which can significantly disadvantage workers with seasonal, temporary, or overtime pay. They may have to pay inflated PACs, compared to their annual income, or even lose their coverage—another way that affordability hinders HIP Plus membership.Nonprofit organizations, with the exception of health providers, are allowed to pay people's PAC.

According to FSSA data, in Demonstration Year 3, nonprofit organizations paid PAC for 9,381 HIP Plus members at an average of $14.06 per member.[18] Nonprofits across our state have a donor campaign and funding opportunity that could dramatically improve health benefits for the 100,000 Hoosiers currently on HIP Basic who earn 50% or below of FPL. Estimated price tag? $1,769,136. Benefits and wellness gains for the new HIP Plus members? Priceless. Additional funds could help people who currently do not have any HIP coverage move onto HIP Plus.

> Few applicants know to check if their current primary care provider is part of an MCE's network or if their key medicines are in an MCE's drug formulary.

Finding 8: Members Rarely Select MCEs

Currently HIP health plans are offered by four MCEs, Anthem, CareSource, MDWise, and MHS. Their plans differ in covered benefits, provider networks, drug formularies, and, sometimes, supplemental supports for employment, housing, and other services. Choosing one's MCE is meant to be a key component of the consumer-driven features of HIP. Members can select their MCE when they first apply or during the annual selection period from Nov. 1 to Dec. 15.

According to the navigators and financial counselors at two different locations, few applicants know to check if their current primary care provider is part of an MCE's network or if their key medicines are in an MCE's drug formulary. As a result, most applicants do not select an MCE, and are assigned one by a broker. Once again, lack of centralized information is a barrier. Several interviewees and one entire focus group complained that there is no web-portal where they could easily compare MCEs' networks, formularies, and benefits, similar to HealthCare.gov for Marketplace health plans. Interviewees report that they first have to pick an MCE and enroll in their online patient system before they can research the MCEs' full benefits package. At that point, they have to wait until the annual enrollment period to shift MCEs, possibly disrupting their relationship with a longtime provider. Informed consumer choice of MCEs does not appear to be supported by FSSA's enrollment process or the MCEs' websites. Unsurprisingly, only 3,769 HIP members chose a new MCE during the 2018 annual selection period.[19]

Finding 9: POWER Accounts Do Not Influence Health Spending

Every month MCEs mail POWER Account statements to their HIP members. The statements list the cost of the previous month's health care visits and the next month's PAC (if any). Tracking the expenditure of one's Power Account funds is another important consumer-driven feature of HIP. This is where members can exercise their "skin-in-the-game" as informed and judicious health care consumers.

When asked, interviewees acknowledge receiving them, But no one reported using their POWER Account statement to exercise spending discretion: "I look through it when I'm in the bathroom and then throw it to the side." (Interviewee 10)

Only one interviewee reported reviewing the statements to see how much her services cost—and only out of a horrified curiosity about the high cost of health care. No interviewees reported knowing that they can rollover unspent PACs and apply them to future years' PAC, though some did report financial rewards from MCEs for wellness visits.

Finding 10: HIP Basic Frustrates Effective Health Care

Most of the HIP Basic users in the study participated in our focus groups. Only two of the HIP-eligible interviewees ever used HIP Basic; one switched to HIP Plus, and the other lost his coverage, presumably by not completing the annual redetermination. Despite this low representation of HIP Basic members, two themes were clear:

1) HIP Basic's co-pays inhibit members' visits to primary care providers and purchases of prescription medicines.

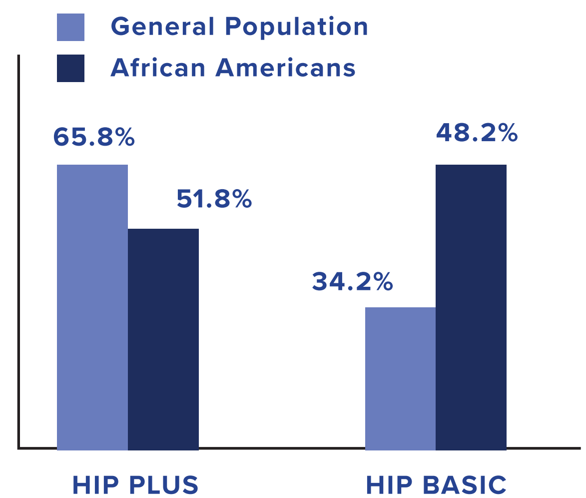
2) With no vision or dental coverage, HIP Basic members do not access these services.

One interviewee described his frustrations with HIP Basic. Although he overstated the $4 co-pay for office visits and preferred prescriptions, this man swore he would never return to Basic.

"With HIP Plus, I can go to CVS or Walgreens and hook up with Money-Gram and you can send your $1, $2 payment [to the Power Account], and there's no fee to do it...With HIP Basic, right, right, you've got to pay $5. I have six or seven medications. And you figure $5 a piece, that's $30-$35. And then when you go see the doctor, $10-$20 co-pay." (Interviewee 8)

Two advocates from Shepherd Community Center described one HIP Basic member's struggle to heal his lingering pneumonia. Instead of a $1 per month premium, he has co-pays for every service: "We've got a guy that goes, and he's had pneumonia for six weeks, finally drives himself to the hospital, is sent home with a script, and he's back, and back, and back, and back because he can't afford the three or four dollar co-pay for that medication." (Community Leader Group 4)

The disproportionate representation of HIP Plus members in our interviews reflects the selection bias of working with community partners to recruit their more-connected members and neighbors. Despite majority representation of African Americans among our interviewees, our results do not clarify why African Americans are on HIP Basic at much higher rates (48.2% on HIP Basic compared to only 34.2% of all HIP members). This question needs further study.



Finding 11: Transportation and Unreliable Medicaid Cabs Are Major Barriers

At Shepherd Community Center, transportation was consistently cited as a barrier to health care. Several interviewees reported success in using the bus system to travel to downtown appointments, but a majority of focus group participants were united in their criticisms of the Medicaid cab system that provides transportation to health care visits and pharmacies. Concerns included the following:

1) ordered cabs do not always pick up their patients,

2) drivers may refuse to offer rides to distant providers because the fee is inadequate,

3) family members may not travel in the cab, including the children of patients,

4) patients have no secure system of knowing the identify of their driver

5) patients have no warning that drivers have arrived to pick them up.

A paramedic who works with Shepherd Community Center described the barrage of complaints he gets about the Medicaid cab system: "Our neighbors all the time, I mean all the time, we're hearing my cab never showed up, I called the operator and they said it hasn't been picked up yet. Your ride, that order number, has not been picked up by any driver. That's a problem....Meanwhile you've been

> "Meanwhile you've been waiting six months for 15 minutes with your doctor.... The cab never shows. Now you're put back in the queue. So delays – so you've got cab drivers that are stopping forward momentum with people's health care, not just one or two at a time."

waiting six months for 15 minutes with your doctor.... The cab never shows. Now you're put back in the queue. So delays – so you've got cab drivers that are stopping forward momentum with people's health care, not just one or two at a time." (Community Leader Group 4)

These transportation problems may not register high with FSSA because the 2015 HIP waiver removed Medicaid's standard non-emergency transportation benefits. Recognizing the importance of medical transport, most MCEs offer some Medicaid cab or bus pass benefits, but the amounts are often too restrictive. For example, a recovery coach explained that patients in long-term opioid recovery need transportation to a Methadone clinic twelve times weekly (two one-way trips per day six days of the week), but their clients were limited to 20 bus passes per month.

Finding 12: Members Find MCEs' Benefits Too Limited

Despite general satisfaction with HIP Plus (not HIP Basic) plans, some interviewees and many focus group participants expressed frustration with their MCE's limits on the provider networks and drug coverage. People reported losing a beloved provider and being denied a prescription written by their physician.

Challenges with restricted provider networks and formularies are familiar to almost anyone with health insurance. Although she appreciated her HIP Plus, one interviewee doubted that HIP is equal to private insurance. "If you work at Lilly, or you work at a better place, you don't get the same kind of care....A certain doctor may look at you and say, okay, we're going to fix her because she's got HIP. Oh, but she's got this insurance over here, she works at Lilly, she carries this insurance, we're going to fix her up, we're going to give her this much therapy." (Interviewee 13)

Our interviews and focus groups provided a clearer picture of HIP's enrollment cycle than HIP utilization. Quantitative research into HIP members' health care access and health outcomes is needed for an in-depth assessment of HIP utilization.

> According to FSSA's data from Demonstration Year 3, nearly one in four of the people who were on HIP or were approved at some point between Feb. 2017 to Jan. 2018 were out of the program by the end of this period

Finding 13: HIP Loss Rate Is Very High

Over half of our interviewees report losing HIP at some point. Losing HIP coverage almost seems like a matter of course. Asked to rate their experience with HIP Plus, interviewees give high marks. Asked if they have ever lost their HIP, many of the same people say yes, one or more times. Some interviewees report receiving cancellation notifications in the mail, but others learned their coverage had lapsed when they visited a physician or pharmacy and were denied service.

Our interviewees stories match the data on HIP's high rate of churn. According to FSSA's data from Demonstration Year 3, nearly one in four of the people who were on HIP or were approved at some point between Feb. 2017 to Jan. 2018 were out of the program by the end of this period. The numbers give a fuller picture of the scope of the issue:

- "as of January 31, 2018, the end of Demonstration Year Three, [HIP] had 403,075 fully enrolled members,"
- another 19,648 individuals were conditionally approved, and
- another 133,598 "unique individuals who were ever-enrolled in HIP" during that year were neither on HIP nor conditionally approved.[20]

Finding 14: Members Do Not Understand Coverage Losses

Interviewees and focus group participants mostly do not know why their coverage is suspended or terminated. In the Introduction, we told the story of a man who lost his HIP Plus coverage for 6 months. Despite help from a social worker, financial counselor, and paramedic, he never learned why he lost his coverage. Interviewees speculate that job changes, which FSSA can track in some cases, are one major reason why they lose coverage. Members' earnings may rise, increasing their required PACs or pushing them above HIP's income level of 138% FPL. This appears to have happened to the young mother whose story we also included in the Introduction, but she never understood the termination of her HIP coverage.

Other challenges include moving residences, which is common in lower-income areas, and missing FSSA's mailed requests for annual redetermination or other documentation. Changes to household membership can also affect income levels and program eligibility. One woman struggled to keep her insurance when her mother moved in with her, resulting in FSSA confusing their two cases. "My Mom then moved in, and they put everybody on one case. No, my case is my case. Her case is hers, because to me you're violating HIPAA. Just because we live in the same house does not mean we are one." (Interviewee 2)

Finding 15: Status Updates and Redetermination Require Better Support

According to FSSA's data, here are the top five reasons why HIP benefits were closed by the state during Demonstration Year 3:

1. "Individual failed to comply with or complete redetermination" (50,515 people)

2. "Income exceeds program eligibility standards" (27,204)

3. "Failure to provide all required information" (15,347)

4. "Receipt of or increase in earned or self-employment income" (13,203)

5. "Failure to make payment to Power Account" (11,795)[21]

Two of these five reasons reflect changes to people's income that affect eligibility or compliance with the program. The other three, which affect the largest number of people, are all characterized in this report as individual failures. The language of failure deflects responsibility from other parties—e.g., FSSA, MCEs, call center—onto noncompliance by the individuals who lost or never gained coverage.

Listening to the lived realities of interviewees' experiences puts in context Indiana's very high loss rates of HIP coverage.

- Homeless people and other vulnerable Hoosiers needing out-of-state birth certificates will "fail to provide all required information."

- People who move their mailing address without updating it will likely "fail to make payment to POWER Account."

- Interviewees' reported problems with the state losing documents will contribute to "failures" of redetermination.

The expectation that HIP members take ownership as responsible, engaged consumers does not appear to be matched by ownership-taking by FSSA, MCEs, or Maximus in being fully transparent about their processes and requirements and actively assisting HIP members in navigating them. It would be interesting to survey HIP members who lost benefits to ask if any one of these parties fell short in their responsibilities to support members.

The leader of the Wellness Ministry at one partner congregation raised the question of FSSA's responsibility clearly:

"When I worked as a case manager, I had approximately 30 cases to work on. Well, I went to see most all of them on the first day, and some of them I could solve their problem, [but others] I had to put them on the list to go back to the next day, and the next day, and the next day. That was my job, to make sure that people got the services that they were supposed to have. I couldn't just say, okay, well I'm just going to leave this one alone because they're uncooperative or whatever, because it was my responsibility to see that when that person left the hospital they had what they needed. That was the hospital's policy. HIP needs to have that policy in order for them to

be successful. [HIP needs] to own the process, the whole process…. HIP needs to own that and do the follow-up in order to make their product successful." (Leader Group 3)

Finding 16: Gateway to Work Will Likely Compound HIP Losses

Indiana has begun implementing the new Gateway to Work requirement for HIP. According to FSSA data, 71% of HIP members are exempt from the requirement. If not exempt, members must work, volunteer, or attend school—20 hours per month starting July 1, 2019 and ramping up to 80 hours per month as of July 1, 2020. Some 27,000 people already meet the reporting requirement through paystubs they submit. Another 73,000 will have to report hours by completing online forms or calling their MCEs.[22] Members who do not report sufficient hours 8 of 12 months of the year will lose their HIP benefits.

"[HIP needs] to own the process, the whole process…. HIP needs to own that and do the follow-up **in order to make their product successful**"

Of the 38 people who participated in our interviews and focus groups, none reported needing to report Gateway to Work hours. Some of them had received a letter with an exemption. A few had received a letter stating that they work sufficient hours and do not need to report. Some had never heard of the program, and most had questions. Given the size of our study, it is hard to believe that no one is required to complete Gateway to Work reporting. Member awareness of the program is spotty. It is very likely that HIP members will lose benefits because of reporting problems even if their hours meet the law. FSSA's usual communication strategies of mailing letters and posting explanatory information and a video on their website will not reach all affected Hoosiers. MCEs are conducting their own outreach. As Gateway to Work rolls out, we urge the FSSA and MCEs to develop new communication strategies.

Proponents of Gateway to Work argue that it is designed to link HIP members to jobs, education, and community service that enable them to develop skills and social connections to ultimately gain financial stability and leave public assistance. This hope for a supportive progression from HIP to a job with health benefits is difficult to square with our interviewees' experiences.

On the one hand, some interviewees report challenges that will hinder their obtaining the required hours. Common issues include having only seasonal work, being injured or unwell without a legally classified disability, and lacking skills or transportation for jobs.

On the other hand, some interviewees already face, or have experienced, losing their HIP benefits when their income rises. One community leader's staff lost their HIP benefits with a raise to $10 per hour—a terrible bind for an employer. HIP's income cut-offs are very low. For people working 40 hours per week, they are:

- $9 per hour for a single individual
- $12 per hour for a family of two
- $15.50 per hour for a family of three

It is likely that Gateway to Work will push more HIP members over the benefits cliff without a parachute to smooth the transition. We interviewed a woman whose PACs have climbed from $1 a month to $20 a month as she went from no income while in a recovery program to a steady job. She described how working mandatory overtime hours last winter had already put her HIP benefits in jeopardy. In her assessment of Gateway to Work, "The state wants you to better yourself but then penalizes you for it." (Interviewee 13)

Finding 17: Communication Breakdowns Are Pervasive

Although this operational finding comes last, it affects the entire HIP process. Communication breakdowns were a recurrent issue in all of our interviews and focus groups. The primary causes are:

"The state wants you to better yourself but **then penalizes you for it.**"

1) FSSA's mailed notifications (a requirement of the federal Medicaid program) and their length and technical terminology,

2) the call center's apparent function of referring, not resolving, HIP members' problems,

3) the initial hand-off from FSSA to MCEs when HIP members are conditionally approved,

4) the lack of duplicate means of more active outreach (e.g., phone calls and case management) or use of other technology (e.g., emails, text messages, and social media platforms), and

5) the lack of a centralized tracking system where HIP members can check the status of their application, documents, coverage, required updates, and annual redetermination.

One interviewee's comment is representative of the many concerns we heard.

"With HIP Plus—I've had different insurances—I think they have the right thing in mind. It's just they do have some things they can work out in the sense of making sure that their customers know what everything is. Quit sending all of these papers, people are not reading that. Call them. Talk to them. When you sign them up, they've got to make these payments, speak to them, make it more personable. I know it's 2019 and everybody wants to use technology to do everything, but you still have to be personable. You still need to have that human interaction to come together." (Interviewee 2)

We are not suggesting that FSSA stop mailing notifications, but letters are ineffective by themselves. For example, when applicants are conditionally approved, their MCE could call, text, or email them, in addition to mailing a plan summary and first PAC invoice. FSSA may not be equipped to conduct the kind of phone and community outreach envisioned by this interviewee. MCEs should have the financial motivation to ensure that members progress from conditional approval to full benefits and remain in the program at annual redetermination. The gaps among the multiple entities responsible for HIP are clearly a major cause of communication breakdowns.

"Quit sending all of these papers, people are not reading that. Call them. Talk to them. **When you sign them up, they've got to make these payments, speak to them, make it more personable.**"

Terminology is another challenge. People still associate Medicaid with the pre-ACA populations of people who cannot work, including children, pregnant women, and disabled adults. When she first learned about HIP, one woman assumed that she would not qualify because she worked and was not pregnant. Another woman voiced skepticism, too: "Even though I'm Nana, and I don't have dependents in my home, I can still be in that [HIP] program?" (Interviewee 4) The existence of multiple HIP programs (Regular vs. State; HIP, HIP Maternity, Transitional Medical Assistance), along with the other state plans, Traditional Medicaid, Hoosier Healthwise, and Hoosier Care Connect, also confuses people about eligibility and deters some people from applying for coverage.

A clear finding of our research is that HIP members who work with certified navigators, financial counselors, case managers, community health workers, and other supportive connectors fare much better with their HIP applications and coverage. Communication breakdowns are a major reason why this person-to-person support is critical.

HIP members who work with certified navigators, financial counselors, case managers, community health workers, and other supportive connectors fare much better with their HIP applications and coverage.

Key strategies include:

- One group of certified navigators routinely asks new applicants to authorize them to receive mailed notifications and advocate with FSSA, providing back-up in case the member misses or misunderstands a notification.

- Navigators, financial counselors, case managers, and community health workers know whom to contact to trouble-shoot problems because call center information is usually not the final word.

- These connectors can access information about the status of HIP members' applications, coverage, and documents.

While this support is invaluable, better communication is critical for individuals navigating HIP on their own.

Study Neighborhoods and Community/Congregation Support

This research is community-based and participatory. We heard people's lived experiences with health and health care and listened to their solutions. We gathered local knowledge about the two study neighborhoods from low-income residents and congregants and from leaders at First Baptist Church North Indianapolis, Shepherd Community Center, and their community partners. The next set of findings highlight some of the neighborhood challenges faced by our HIP participants along with some successful or promising model support strategies.

Finding 18: Social, Economic, and Environmental Barriers Intensify Health Disparities and Disengagement

HIP is health insurance for people living near or below the Federal Poverty Level. Although FPL is a measure of annual income, poverty affects much more than economic standing and opportunity. People living in poverty typically face reduced standing socially, culturally, politically, educationally, and technologically. Interviewees identified a variety of barriers that frustrate good health.

POVERTY FRUSTRATES PEOPLE'S ABILITY TO NAVIGATE AND ADVOCATE

"Poverty frustrates people's ability to navigate and advocate in health care." (Community Leader Group 1) This statement from a leader at Shepherd Community Center crystalizes two realities:

1. Successful navigation of a complex health care system requires access to a range of resources and supports.

2. Successful care requires personal advocacy to get one's health situation acknowledged and claim effective help when needed.

These navigation and advocacy challenges are not unique to people living in poverty. But HIP increases their likelihood because members typically do not select their MCEs and are assigned providers they may not know. Now starts the process of learning new scheduling, billing, and communication procedures and, more importantly, re-establishing a relationship of trust built on accumulated health knowledge. For HIP members with children, their provider and their children's providers will normally work in different locations, a concern reported by several interviewees and focus group participants.

> "Let's not forget the main [barrier to health], money…. **it's hard to trust the system,** whenever the first question is can you pay."

HIP's cost-sharing requirements intensify the challenges of accessing trusted health care. A physician who partners with Shepherd explained, "let's not forget the main [barrier to health], money…. it's hard to trust the system, whenever the first question is can you pay." (Community Leader Group 1) Another leader noted the "predatory" nature of many local businesses. He gave an example of a family living on $700 per month that paid directly to their landlord. After rent and utilities, the family had "$40-$50" for their other monthly expenses, putting HIP's PACs or co-pays out of reach. (Community Leader Group 4) For some interviewees, decades of hard labor exacerbate poor health and health care vulnerability.

In addition to monetary struggles, the most commonly mentioned barriers to staying healthy are:

TRANSPORTATION

The congregants we interviewed at First Baptist Church North Indianapolis all had access to private transportation, reflecting their generally higher socio-economic standing. At Shepherd five of the six interviewees were entirely dependent on public transit and Medicaid cabs for health care. A Shepherd leader described the complex web between health and transportation for many HIP members. "I think transportation is a big, big part. It's not just cab rides to the doctor. It's also let's use this to take folks to the grocery store. We talk about this is a food desert. You've got to buy an extra ticket, if you've got more than two bags of groceries, to get on the bus." (Community Leader Group 4)

This "three bags two tickets" policy is likely unknown to most Indianapolis residents who are not bus-dependent. With busy lives and tight budgets, shopping for a week's groceries saves time and facilitates healthier home cooking. People who are bus-dependent and trying to eat healthfully face a punitive barrier of having to pay twice for bus transit. The cost may seem slight to the bus company wanting to protect seating, but low-cost barriers like this one are prohibitively high for people living in extreme financial constraints.

FOOD DESERT

The Shepherd neighborhood has two groceries. The larger more affordable option is only a mile but still a two-bus, downtown-and-back trip each way. There are no grocery stores near First Baptist Church North Indianapolis. One interviewee marked the change from when her grandmother lived in the neighborhood. "So, okay, I'm hungry. Where am I going to go? And it's a nice trek from here to McDonald's, Burger King, no grocery stores though. It's just not a lot of healthy food selections around here. That's really sad because literally they closed. When I was a child...I would walk from my grandmother's house which was a couple of blocks back, to this defunct grocery store on the corner.... my grandmother never drove.... Now, if my grandmother were alive today, where is she going to go? You have to catch a bus to get to a grocery store. That just doesn't sound like that's even fair."(Interviewee 5)

Flanner House recently opened a new bodega a few blocks from First Baptist Church North Indianapolis, and other bodegas have served the area. Interviewees recalled a bodega run by a beloved man who gave credit to neighbors and small gifts to children. In some neighborhoods, economic viability may limit residents to these smaller-scale nearby food options, which is why interventions by nonprofits can be critical to lower prices and healthier food choices.

MENTAL HEALTH

Interviewees at both community partners cited situational and chronic mental health challenges as common health conditions and health barriers. The First Baptist Church North Indianapolis pastor cited trauma as a challenge for many young people growing up in the neighborhood. Interviewees drew connections in their own and others' lives between a history of trauma and mental illness, for which self-medication with drugs or alcohol is sometimes a response. Under-provision of quality mental health services contributes to poor health outcomes and health disparities.

Mental illness is an aggravating factor in some people's disengagement from HIP. As one interviewee said, "People don't realize when you go into depression, processes can be depressing." (Interviewee 8) Another interviewee described his dislike of group therapy and his depression medication as the reason he let his HIP Basic lapse and stopped visiting his mental health provider, whom he acknowledged would be angry with him. Although he enjoys time with neighbors and services at Shepherd Community, some days he spends "anxious, and just nervous about anything. And, you know, my days sometimes just be depressed. I'll sit a lot of times just sitting in the window just looking at traffic." (Interviewee 10)

By contrast, another Shepherd interviewee reported regular mental health support and effective medication management for her schizophrenia. She is covered by Hoosier Care Connect, a more comprehensive coordinated care program for adults who are 65 or over, blind, or disabled but are not eligible for Medicare (as a result, she is not included in our HIP results). With her benefits, a nearby provider not only delivers her medicines monthly also but has a therapist who arranges visits near the woman's home.

STRESS

Another health challenge is stress. An interviewee being treated for Crohn's disease identified stress as

the major health factor in his life. "The stress, I mean I can't get away from the stress. I'm just saying I try but I can't even concentrate on maybe reading a book or just doing other things. My concentration stays on my family and what I do here at First Baptist. I don't know. I would like to get the stress off of me and see how I do then. But you've got to know how." (Interviewee 3)

The public health literature identifies stress as a key factor in health disparities, partly due to the stigma and obstacles of discrimination, dramatized by the racial disparities in infant mortality. Lower infant mortality rates correlate with higher education levels. Yet Caucasian women who have not completed high school still have lower infant mortality rates than African-American women who are college graduates, underscoring the high costs of stress.[23]

> "People don't realize when you go into depression, **processes can be depressing.**"

STIGMA

Public programs like HIP are frequently stigmatized, and a number of interviewees described feeling a lack of dignity and respect from some state, MCE, and call center representatives. As a young child, one interviewee swore she would never seek any public assistance having experienced the humiliating disregard that aid officials showed to her grandmother. As an adult with the "pre-existing condition" of a pregnancy, she finally applied for the original HIP plan as her only option prior to the Affordable Care Act's protections: "when I was just really running out of my options where I just knew it was something I had to address, and I had to go and swallow my pride and go into the offices. But, they're not always the friendliest. Some are. Some aren't. It's just like anything else. And I get that too. But it is a humbling process." (Interviewee 5)

Changes to the delivery of public assistance have reduced occasions for stigmatization in public. The ACA transforms Medicaid from a social welfare program to a social guarantee for low-income Americans, at least in states that expanded it. Nationally 1 in 5 Americans are covered by Medicaid and the Children's Health Insurance Program (CHIP).[24] The state of Indiana downplays HIP's being a Medicaid program, presumably to lessen any barriers of stigma.

MISTRUST

Mistrust of the health care system remains a substantial barrier, according to interviewees. As described by one neighborhood leader, a "reoccurring theme in people accessing health care and going to health care is this overall mistrust. There's a lot of really good – a lot more – services that are much better than in previous years that people don't access because of the history, historical things that has happened to those communities." (Community Leader Group 2) A local school nurse witnessed, a decade earlier, an African-American woman with diabetes being refused insulin at a local clinic. In her words, "I always think they can step up their game. That's just me. Step up their – the way that they treat people, and talk to people, and how they handle things. There's no way that they should be treating – especially our senior citizens. She didn't know. She was confused. She wasn't even understanding. And there was nobody there to help her. That's why I went up there and helped her out." (Community Leader Group 2)

> The ACA transforms Medicaid from a social welfare program to a social guarantee for low-income Americans

Mistrust can extend to people's interactions with community organizations. A paramedic affiliated with Shepherd Community Center reported, "You'll be surprised at how many people are genuinely thrilled when they say you actually came back. It's like the neighborhood is conditioned to be disappointed." (Community Leader Group 4)

POOR INFRASTRUCTURE

Among the neighborhood conditions that make it hard to stay healthy, interviewees cited problems with infrastructure:

- abandoned and decrepit houses,
- unsafe or missing sidewalks,
- lack of street lights and green spaces, and
- limited access to computers and the internet.

These conditions affect health and safety for residents individually and collectively. With the transition from a "front porch society to a back deck society," neighborhoods have lost the built-in safety of a community of eyes at every window. (Community Leader Group 2)

One interviewee listed the challenges he faces as a homeowner living among abandoned houses:

> "There's a lot of really good – a lot more – **services that are much better than in previous years that people don't access** because of the history, historical things that has happened to those communities."

- "It's hard to stay healthy when you live in between two vacant houses that nobody seems to care anything about. I would like to be able to see my children come outside and play, but it's not feasible."
- His insurance company threatened to cancel his homeowners' policy if he did not cut down a tree that grew over his roof from one of the neighboring lots, at a high cost to him.
- Previously the city cleaned out sewers, but no more. "The sewers are still there. The thing you see is the raccoons and stuff going in and out of them....our water system, it's terrible. We even had somebody come to here from Citizens Energy Group to tell us how bad the water was."

Given this constellation of intersecting problems, "After a period of time, we just become adapted to it, that this is what it is. This is what we got – we've just got to deal with it. There ain't no options." (Interviewee 3)

INCARCERATION

Leaders at First Baptist Church North Indianapolis stressed how much the legacy of tough-on-crime legislation severely disrupted neighborhood families and individuals' lives. One community leader, who was involved with drugs in the 1980s, observed the stark difference in public policies and funding in today's "opioid epidemic" compared to the "war on the drugs." "It was all about locking them up.... Now, they are good kids, they just got off the path, let's give them another opportunity, let's give them a chance... when it was a war, guys got no chance, three strikes and you're out. There are guys in prison in Indiana that got 30 years for having marijuana possessions. That don't make sense." (Community Leader Group 2)
Very supportive of the new emphasis on rehabilitation, he notes the debilitating and lasting effects on the economic viability of families and the communal vitality of neighborhoods when large numbers of young people are imprisoned with lengthy sentences.

PUBLIC SAFETY

Gun violence was cited as a critical health threat by two interviewees with personal experiences. Concerns about crime, prostitution, and drug use were voiced mainly at Shepherd Community. One interviewee explained that he lost access to a gym facility when it changed owners and they stopped accepting visit vouchers from a nonprofit organization. Asked if he walked in his neighborhood for exercise, he replied, " Well, not so much my neighborhood because I live in a bad neighborhood." (Interviewee 11)

Another interviewee described his block as "real good, except for the people across the street. And, it's a drug house, but we can't do nothing about it. But we see cops there at least three times a week. Oh, yeah, fairy lights. And in the middle of the night, an ambulance comes there because somebody's overdosing." Otherwise, this man described an integrated street with neighbors helping neighbors. It is important to stress that these observations were few and refer to isolated events. Overall most interviewees are optimistic and make the best of their situations and neighborhoods.

Finding 19: Person-to-Person Support Is Essential to HIP Success

While some of our interviewees navigate HIP and health care through personal endurance, the vast majority cited the importance of person-to-person support in successfully enrolling in HIP. Connectors include certified navigators, financial counselors, care coordinators, case managers, social workers, recovery coaches, community health workers, and community organizations. They provide information and expertise to cut through the complexity of HIP's procedures and, in some cases, link members to

complementary services. A police officer affiliated with Shepherd described the challenge, "I am a suburban-raised, upper middle class, well-educated, high-ranking school graduate, a little college under my belt, 15 years doing this job, and some of these systems are still hard to navigate for a guy like me." (Community Leader Group 4)

Personal support with HIP applications and enrollment is a first step. More personal exchange is often required for successful HIP navigation and improved health outcomes. As one interviewee noted, "Everybody has a story." (Interviewee 5) Hearing people's stories opens up the fuller context of people's lives, allowing for better understanding of their specific constraining circumstances as well as possibilities for hopeful agency. Interviewees are deeply appreciative when someone takes risks or extends significantly to provide them support. Some of the best resource connectors are those who helped interviewees feel more capable and autonomous. These supporters exemplify the idea of walking alongside participants and meeting them where they are.

Overall most interviewees are optimistic and make the best of their situations and neighborhoods.

IDENTIFYING ROOT CAUSES

We describe Shepherd Community Center's Shalom Project more fully below. This police officer-paramedic duo illustrate the transformative potential of person-to-person support that takes the time to identify root causes of people's health and quality of life issues. They described a woman from neighborhood who was taking ambulances to different hospitals almost every day. During a visit to her house, they learned she has hemorrhoids and "a lot of anxiety along with that. She thinks she's bleeding internally, she's dying... And we're able to kind of educate her and say, look, has the emergency room ever done anything for you? Not really. Why aren't you going to see your primary care doctor? Well I don't know how to get there, I don't know when it is, I don't know how to make the appointment. We spend an hour total probably, not only educating her on how to call the Medicaid cabs, how to get your doctor's appointment, but also to kind of empower her to say, look, this is something that you can do.... a month goes by and we check up on her. She's got appointments scheduled out. She's got rides scheduled out." (Community Leader Group 4)

"I am a suburban-raised, upper middle class, well-educated, high-ranking school graduate, a little college under my belt, 15 years doing this job, and **some of these systems are still hard to navigate for a guy like me.**"

SHARED HEALTH JOURNEYS

One example of person-to-person support at First Baptist Church North Indianapolis is their Lafiya Wellness Ministry. Among their activities, they have a healthy living class. Interviewees told stories of two men with diabetes who lost significant weight. One of the congregants, who was recently diagnosed with diabetes, began eating regularly "so you're not eating, when you're getting ready to eat, the wrong things or too much of something." In seven months, he lost 60 pounds and significantly dropped his A1C levels. Then he closed the circle and shared his story. "Me being an example sharing, and I've shared with some of the men, some of the women in the church about that. I think that's key." (Community Leader Group 3) One reason why this personal sharing of health journeys can work is the social support for developing and maintaining new habits. Creating spaces for sharing health journeys also lessens the fear of having one's individual choices judged.

SUPPORT GROUP SESSIONS

Although unintentional, our focus groups modeled a strategy for person-to-person support for HIP members. Congregations and community organizations could hold support group sessions both to help HIP-eligible people apply and successfully enroll and to use benefits effectively. Our focus group participants taught each other:

1) why HIP Plus is a better deal than HIP Basic,

2) how case managers help navigate mental health challenges, and

3) how to order diabetes test strips through HIP Plans.

Congregations could sponsor support group sessions for their HIP-eligible members and neighbors wanting to learn how to enroll in HIP or make better use of their benefits. The sessions would harness members' collective knowledge

and help allay any lingering stigma around the program. In addition, congregations could consider the personal support of paying congregants' and neighbors' PACs.

COMMUNITY AMBASSADORS

One interviewee proposed the idea of community ambassadors to help homeless people and other vulnerable groups connect with and navigate HIP. Living in a homeless shelter himself, he is adept at navigating HIP and has the qualities of a natural leader. "I've got this aura about me where I can be on the bus and someone just get on the bus and start talking to me, telling me their problems. I'm like, do I got counselor written on my plan?.... what we need to do as a community is get some people out there on the streets and see who needs help. Walk up on them and say did you eat today, did you take a bath today, do you need me to take you to get a bath, something to eat, some clothing. You need to put more out there to help the people that need help." (Interviewee 9)

MCE SPONSORSHIP

Interviewees had surprisingly little to say about the MCEs managing their HIP plans. A few mentioned occasional phone calls to clarify benefits or other issues. Some reported MCEs calling them with reminders to complete annual redetermination and other updates. We encourage MCEs to partner with congregations and community organizations to host support group sessions for HIP members and HIP applicants. They could sponsor community ambassadors at homeless shelters. They might also help support a statewide campaign across congregations of all religions to raise funds to pay HIP Plus members' PAC. Imagine a Get HIP Sunday, Get HIP Saturday, and Get HIP Friday campaign each year. Instead of direct support, one focus group mapped out a strategy for MCEs to use social media to run online discussion forums for members' questions on topics ranging from how to enroll in HIP to how to manage common chronic health conditions.

Finding 20: Organizational Relationships Are Vital to Wellness and Empowerment

Shepherd Community Center and First Baptist Church North Indianapolis both invest in building relationships and trust with the people they serve. Shepherd runs extensive community programs, including a school, financial literacy training, job placement services, cooking classes, recovery programs, and a food pantry. Some of the people served

"What we need to do as a community is get some people out there on the streets and see who needs help. Walk up on them and say did you eat today, did you take a bath today, do you need me to take you to get a bath, something to eat, some clothing. **You need to put more out there to help the people that need help.**"

attend their Sunday Celebration Church service. First Baptist Church North Indianapolis is a church that extends their ministry into the community through weekly feeding programs for neighborhood adults and schoolchildren, a food pantry, clothing closet, Friday night youth gatherings, and other supports provided by church volunteers. in the pastor's words, "African American churches' calling down through the years requires us to have allegiances to these principles [of caring for widows, orphans, and strangers]...we're supposed to be about the business of resourcing people and helping people, because that's what ministry is." (Community Leader Group 2)

Although our community partners take different approaches to congregational and community support, building relationships and trust is essential to their program design.

SHEPHERD'S SHALOM PROJECT

As a community center, Shepherd has more staff and resources to invest in relationship-building in their neighborhood. Shepherd takes a holistic approach to building people's capacities for wellness, and many of their programs touch on health. One model program is their Shalom Project. Shepherd employs an IMPD police officer full-time and splits a paramedic with Eskenazi Health. This team follows-up with 911-callers from the neighborhood to start a process of building a relationship, trouble-shooting root causes of health and quality of life problems, connecting people to services, and empowering neighbors to navigate systems.

The first step is relationship. While the reported emergency is being addressed, one team member will work in the background, talking to the family and listening for other issues or concerns. The team will ask to return a few days later, which is when the deeper listening and social assessment begin. "A lot of our folks aren't listened to.

Everyone is trying to solve what they need. Everyone's trying to throw money at what they need. I will tell you we've had some huge successes in building relationships, and getting over some huge obstacles, and the amount of money we throw at the situation is nil. Very, very, very, little money.... We've had folks that their light hasn't been on in a while, and all of a sudden they've got some hope, and now they're ready to tackle some of those things. Some of the relationships have lasted almost our entire trek." (Community Leader Group 4) The money is invested in the team, who have been together for four years. The more they address the root causes of residents' quality of life issues and health care disengagement, the better health outcomes for people and the lower costs to the system, even if the savings are not easily calculated.

Building relationships and trust opens the door to people's networks (or lack of them) as well as some of their life challenges. As described by the team, "A lot of what we do is social work." "Connecting the dots is what it is." "Yeah, connecting the dots. Some of it is being their family." (Community Leader Group 4) Understanding how people connect to social networks helps identify natural supporters for life changes. Understanding people's life challenges as a reinforcing dynamic helps identify needed services. Now with personal knowledge of people's social networks and service needs, organizations can connect people effectively and sustainably to those services or empower people to do it for themselves. The Shalom Project uses a case management model working with a social worker and other support groups at Shepherd. "We're not working in silos. You've got law enforcement. You've got EMS. You've got a community center. We're not working in silos. We're all talking together. Holy cow, it works." (Community Group 4)

FIRST BAPTIST CHURCH NORTH INDIANAPOLIS CONGREGATION

At First Baptist Church North Indianapolis, the primary arena of relationship-building is within the congregation, where people are known in their social networks and often their life challenges. Unlike the emergency intervention of Shepherd's Shalom Project, members encounter each other in a life of shared joys, celebrations, concerns, and assistance. Health and wellness are regular topics through a Wellness ministry that has run healthy living classes and health education programs. As described by one interviewee, the church has "a lot going on with breast cancer, and heart awareness, and things that make you aware. As a female, things we should do as females and things like that. Then spiritually, yeah, it's like a hospital." (Interviewee 6)

SCHOOL 42 RESOURCE STORE

Currently First Baptist Church North Indianapolis is partnering with Holy Angels Catholic Church and School 42 on a Resource Store for neighborhood residents. Its component parts include a room at School 42 with some necessities, a bank of computers, and a database of sources for a wide range of services and needs that includes names and contact information. The Resource Store will be staffed by someone to assist customers both in using the database and, more importantly, in being connected with helpful people at the service and provider locations. The Store aims to empower people to navigate their health, wellness, and other needs through a trusted network of organizational relationships.

> "We've had folks that their light hasn't been on in a while, **and all of a sudden they've got some hope, and now they're ready to tackle some of those things**. Some of the relationships have lasted almost our entire trek."

Finding 21: Spiritual Connection and Community Support Holistic Health

When asked to describe wellness, interviewees often cited the intangible elements of emotional and spiritual well-being they experience in their congregations and communities. A First Baptist Church North Indianapolis interviewee defined wellness as "physical, mental, and spiritual, a holistic wellness...If my mind isn't well, nothing else is going to be well either." (Interviewee 4) Sunday services at this church combine the physical, emotional, and spiritual as congregants join together holding hands and sharing words of mutual recognition and affirmation. Time spent in community is a remedy for stress. "It's more of a spiritual support with spiritual love, just caring. It's bad to say but when I get here, I get that peace of mind." (Interviewee 3) Serving together as a community also promotes wellness for oneself and others:

"We're not working in silos. You've got law enforcement. You've got EMS. You've got a community center. We're not working in silos. **We're all talking together. Holy cow, it works.**"

"My mother's gone. I have a lot of older women that I respect, that – and I'm always learning something. I know what I contribute to the church …I'm a crafty lady." (Interviewee 1)

Congregants take this holistic understanding of health into their professional work, as described by a First Baptist member who works for the Homeless Initiative Program: "When it comes to health, it's not just whether or not you've got a cold, or you've got cancer. You want to focus on everything, because if I'm not working, I'm not going to the doctor. Right? If I'm not eating, I'm not worried about going to get a flu shot. Our focus is we come into neighborhoods that are experiencing some poverty, and we look out for the whole individual. We have clothing rooms. We have food pantries.... We have people come in if they're just cold and want to get off the street.... Hygiene items, if they want to get cleaned, we allow them to come into the bathroom and wash up.... we do have money where we can help people pay bills, pay their rent if they need to. We can offer bus passes. We do have job fairs that's open to everybody, and our employers do hire on the spot." (Community Leader Group 3)

At Shepherd, interviewees stressed a commitment to compassion and welcoming people from all walks of life. In the words of one woman managing significant mental health challenges, "Wellness means friends. It means Shepherd. It means family." In addition to Celebration Church services, she has participated in Shepherd's food pantry, Bible study, holiday events, and former community garden. "It's a routine. It's constant. It's a constant part of my life. The other people, I know them; they know me. I'm used to their love. I'm used to their friendship and their concern." Another interviewee described Shepherd's neighborhood outreach in Gospel terms, "They just really are very helpful with everyone and reach out to everyone. It's not like a pick and choose or – I mean, they're really wanting to build the community out there just so free and fair. There's no pick and choose. That's what – just like what Jesus does, and it's beautiful. They'll come after you too." (Interviewee 13)

It is important to note that some interviewees reported congregational judgmentalism that thwarted their health journeys. Discussing the church of his birth tradition, he expressed how distrust and hopelessness depleted his motivation to address his substance use disorder. "I'm not asking you for anything, but understand my struggle and don't kick – don't judge me through it. God's going to bring me through it. I believe that. God is going to bring me through it. But don't kick my butt as I walk – go through it." (Interviewee 8)

The First Baptist Church North Indianapolis pastor champions a different hope, "The hope is that we don't have so much compassion fatigue, or that we desensitize ourselves to the good that we can do because some things don't make sense. Addiction is never going to make sense. Dealing with abject poverty and dealing with lack of good food, and if you're drinking as an adult the same lead water that your children are drinking, then it's going to have psychological effects.... And the trauma that these kids are dealing with specifically. But the trauma that these kids are dealing with is the same trauma that these parents are dealing with, and the environment is just set. And so our compassion and thought and hope always have to be how do we create the system, and how can we confront the realities of poverty, and infuse some hope." (Community Leader Group 2)

CONCLUSIONS: ASSESSING HIP'S POLICY VALUES

HIP's stated "core objectives" include:

• "Make Hoosiers healthier;

• Provide new coverage pathways for uninsured Hoosiers;

• Promote employer sponsored health insurance;

• Create incentives for Hoosiers to transition from public assistance to stable employment;

• Promote personal responsibility; and

• Engage participants in making health care decisions based on cost and quality."

Three fundamental values motivate this list of core objectives: Wellness, Consumer Empowerment, and Personal Responsibility. Propelling these values is HIP's consumer-driven design: "Consumer driven behavior is incentivized by providing members with a Personal Wellness and Responsibility (POWER) Account, which functions similarly to a health savings account."[25]

Having analyzed and summarized our study participants' reported experiences with health, health care access, neighborhood health conditions, and HIP, we conclude by assessing how well the program is meeting its policy values.

Wellness

HIP Plus can definitely improve members' wellness and quality of life. Many HIP Plus interviewees have an established primary care provider; many make regular use of wellness visits, preventive care, and management of chronic conditions. Interviewees stressed how their lives have changed with coverage they can afford that has no co-pays. In the past they never visited a doctor, dentist, optometrist, or therapist because they could not afford it. Some developed the chronic problems they are dealing with now.

One woman's story exemplifies the transformative potential of HIP Plus in transitioning people to wellness along with the tenuousness of this cultural shift if benefits are lost:

"I lost like 30 pounds in a year. I was taken off of the blood pressure pills. I asked [my doctor] if I could be off, and it was stable, so he took me off. Overall, everything is fine. I have my testing when I need to have a testing. I had three appointments set up the other day actually because, it was funny, I knew the insurance was going to run out. I had to scramble around trying to find a doctor to work with my schedule because I'm only off on Thursdays. I'm thumbing through the mail and I'm like, oh, they assigned me someone. I call and they're able to get me in on the last day of the month. So I got my mammogram, and I got to see a primary care physician, the last day of January." (Interviewee 6)

HIP's application process is designed to nudge conditionally-approved applicants onto HIP Plus with the 60-day window for paying the first PAC. The lengthy time-lag for re-applying after losing benefits—or being locked out of coverage—is meant to motivate members to maintain continuous coverage. Promoting continuous HIP Plus coverage is the best route to wellness. But program design confronts hard realities when we listen to Hoosiers living in or near poverty and trying to navigate the complex HIP Process Map. A partnering physician at Shepherd identified how easily the goal of wellness can be derailed: "how do we start to help folks switch their mindset to that kind of preventative care thinking, and that's just counter-cultural in a lot of ways when we're surviving." (Community Leader Group 2)

HIP Basic also frustrates the goal of wellness because its co-pays are a major barrier for anyone with chronic conditions and/or multiple health issues. For people with 5 monthly prescriptions, this cost alone is at least $20 per month, the highest level of PACs on HIP Plus. HIP Basic participants must pay higher co-pays for non-preferred drugs and co-pays for all medical visits.

> "How do we start to help folks switch their mindset to that kind of preventative care thinking, and that's just counter-cultural in a lot of ways **when we're surviving**."

The other threat to HIP members' wellness is the transitory nature of HIP. Over half of interviewees have lost their benefits for often-unknown reasons. We reiterate the following statistic from FSSA's data. In Demonstration Year 3, the most recent data year, 1 in 4 Hoosiers who had HIP benefits or were approved at some time during this year had been churned out of the program by year's end.

> The transformative potential of HIP Plus in promoting wellness results from Indiana's expansion of comprehensive benefits to hundreds of thousands of more people, not from HIP's diminished consumer-driven features.

Consumer Empowerment

The 2008 version of HIP was designed to use some of the tools of consumer-driven health care—health savings account, high deductible, and incentive pricing for primary care over emergency care—to enlist Medicaid users (earning up to 200% FPL) in becoming better health care consumers. Managing one's own money through the POWER Account was intended to get people to ask for the prices of health care, monitor their spending, prioritize wellness and high-value care, and retain any residual PACs year-to-year. HIP continues features of this consumer design and the goal of consumer empowerment. Nevertheless, for our study participants, the transformative potential of HIP Plus in promoting wellness results from Indiana's expansion of comprehensive benefits to hundreds of thousands of more people, not from HIP's diminished consumer-driven features.

For over half of HIP Plus members (52.5%), their monetary "skin in the game" exposure is limited to $12 per year.[26] Even for HIP Plus members contributing at the highest level of $20 per month, the state funds 91% of their POWER Account and annual deductible. The state funds 100% of HIP Basic members' POWER Account and annual deductible. To be clear, we are not recommending that individual members be required to contribute more. We are highlighting the discrepancy between theory and practice. In terms of managing their health care spending, study participants do not monitor the bills listed on their POWER Account statements. Regarding the savings incentive, they do not seem to know about the rollover of any unspent portion of their PACS to the future years, even though 165,928 HIP-Plus members had some of their PACs rollover in 2018.[27] Participants have a vague idea that some MCEs reward wellness visits. But they are not selecting MCEs for their provider networks, drug formularies, or optional benefits like non-emergency transportation.

HIP does promote consumer empowerment. The successful HIP Plus users in our study feel empowered to manage their medical, pharmacy, vision, and dental care needs but not because they are engaging in "making health care decisions based on cost and quality." Study participants report being empowered by HIP Plus' comprehensive coverage and no co-pays and by active support from primary care and mental health providers, case managers, care coordinators, and community organizations. Certified navigators and financial counselors provided critical support during the application phase too. But, oddly, we learned that navigators may not counsel applicants toward HIP Plus or HIP Basic. They can only compare the "facts"—e.g., monthly PAC vs. regular co-pays. In this instance, HIP's emphasis on consumer choice is misplaced. Not recommending specific MCEs is appropriate so long as consumers have clear information to make informed decisions. Remaining neutral between HIP Plus and HIP Basic harms members, who nearly always will end up with more cost-sharing on Basic than Plus. FSSA should allow and encourage navigators, MCEs, and others to educate on the advantages of HIP Plus so that everyone "starts" and "stays" on it.

Personal Responsibility

HIP Plus—and to a lesser extent, HIP Basic—extend vital resources to people to take responsibility for their health and wellness. These programs are "new coverage pathways for uninsured Hoosiers," a core HIP objective. In their absence, the vast majority of HIP members would revert to struggling without viable coverage and relying on emergency rooms as last resort care. Our study participants affirm the value of exercising personal responsibility in using

the resources newly available to them, which for HIP Plus members include medical, vision, dental, and mental health providers; medical drugs and devices; clinics, outpatient procedures and diagnostics, hospitals, and home care; recovery programs; and usually some transportation. Some interviewees report life changes that reach beyond improved physical and mental health outcomes to more stable housing, employment, finances, relationships, and sense of belonging.

Personal responsibility relates to another core HIP objective: "create incentives for Hoosiers to transition from public assistance to stable employment." While interviewees appreciate the carrot of HIP Plus' comprehensive coverage, they experience this objective as a stick of negative judgment pushing them toward the benefits cliff of losing HIP coverage with few or no viable alternatives. With Gateway to Work, the incentive of seeking employment, volunteer service, or education is mostly in the threat of losing HIP coverage for noncompliance or non-reporting, for whatever reason. Similarly, HIP applicants and HIP enrollees have incentives to take "ownership" by stepping up and diligently meeting all of the application, documentation, PAC, and redetermination requirements of the annual HIP process, again on condition of losing or being denied HIP coverage.

This personal responsibility looks less like responsible use of available resources for good health outcomes and more like blame-shifting onto the 1 in 4 people who were either on HIP or approved for HIP during Demonstration Year 3 but were no longer in the program at year's end. The same language of "failure" is used in FSSA's reporting of the top reasons why members' HIP was "closed."

Our study participants feel this client-takes-responsibility-or-else attitude in their attempts to navigate the system. Shadowing the process is the tacit sense that being on HIP in the first place represents failure.

HIP's design is meant to motivate consumers to take the initiative for better health. Initiative is required but often misplaced. With the consumer-driven features of HIP operating in the background and having little influence on members' behavior, in practice, the value of personal responsibility is largely structured into the logistical and bureaucratic hurdles that members have to navigate with little or no understanding of their purpose. This structure feels punitive to members. It is also counterproductive to supporting members' personal responsibility for health and wellness. One congregational leader noted the gap between the expectation of ownership-taking by HIP members and the apparent lack of ownership-taking by the state and partner organizations (MCEs and Maximus) for retaining HIP members.

Personal and Shared Responsibility

A key lesson of this study is that personal responsibility for health does not exist in a vacuum. One reason is geography, especially as it relates to poverty. In the field of public health, ample research demonstrates that zip code is more determinative of health than genetic code. Average health outcomes are affected by the social determinants of health—the social, economic, and environmental conditions in which people are born, grow up, get educated, reside, have families, eat, work, play, and age.[28] Reflecting on his neighborhood, one interviewee personalized this theoretical point about the health effects of "housing, job access, education, income, stress, environment, safety, access to food, everything." In the words of this father of two, "And then what is this going to do to our kids." (Interviewee 3) We hasten to add that study participants are personally resilient and build support networks in their communities.

Another key lesson of our research is that HIP members enroll more successfully with support from certified navigators, financial counselors, and other health connectors. HIP members also navigate and advocate more successfully with support from networks of community organizations, case managers, care coordinators, fellow congregants, family and friends. This study found big differences between navigating HIP on one's own and navigating it with active support—the difference between HIP naked and HIP clothed. HIP "naked" leaves individuals on their own to navigate and advocate for themselves in health care, two tasks made much more difficult by poverty and mental health challenges. When HIP is "clothed" by the personal and organizational support that many of our interviewees—but fewer focus group participants—experienced, HIP works better for individual members and our state.

We call on all of HIP's stakeholders—FSSA, MCEs, providers, health departments, community organizations, congregations, social service nonprofits, navigators,

and others, to develop better-integrated ways of combining personal and shared responsibility in reaching a goal of greater HIP Plus participation and continuity. HIP's structure of combining members' PACs or co-pays with state funds is an expression of this balance between personal and shared responsibility, but more is required to advance its policy values.

> This study found big differences between navigating HIP on one's own and navigating it with active support—the difference between HIP naked and HIP clothed.

Indiana's political culture prioritizes public policies linking personal responsibility to community action through religious and civic initiative. Our research team investigated the implications of this policy approach for HIP and the efficacy of congregational programs in supporting HIP-eligible people in navigating its requirements and benefits and improving their quality of life. At this time, we see an exaggerated policy emphasis on HIP members' personal responsibility without clear policy actions to make HIP procedures more responsive and to engage community action through religious and civic initiative. We hope this report helps close the public awareness gap around HIP and suggests new strategies for strengthening the program through new collaborations.

RECOMMENDATIONS: FUTURE STATE OF HIP

General Recommendations for Improved HIP Operations

In keeping with our people-centered participatory approach, these recommendations flow from HIP members' experiences and insights not from investigation of FSSA, MCE, or Medicaid systems and rules:

1. CREATE USER-FRIENDLY "ONE STOP" HIP APPLICATION/ENROLLMENT TRACKING SYSTEM (SIMILAR TO HEALTHCARE.GOV) WHERE PEOPLE CAN:

a. track the status of their application, documents, coverage, redetermination, POWER Account contribution level, and Gateway to Work exemption or reporting requirement

b. securely upload documents and track them as in-process, incomplete, or complete

c. easily compare MCEs' coverage benefits for their HIP plans

d. access duplicates of FSSA's mailed notifications

2. IMPROVE FSSA AND MCE COMMUNICATIONS BY:

a. simplifying terminology and shortening length of notifications and statements

b. allowing members to authorize email, text, or phone messages and reminders

c. nudging applicants and members to authorize a HIPAA designee to receive duplicate notifications, statements, reminders

d. requiring MCEs to display HIP plan benefit summaries, networks, and formularies on their websites

3. ADOPT AN INTENTIONAL CUSTOMER SERVICE MODEL THAT:

a. tracks HIP applicants' and members' contacts with FSSA, DFR offices, and call center

b. provides workforce incentives to enroll and retain HIP members like "New Indiana BMV"

c. reviews disconnect between call center information and the answers and decisions of FSSA employees

d. reports last point of contact when HIP applicants and members lose or do not enroll in coverage in order to improve support systems

4. MAKE ENROLLING HOOSIERS IN HIP PLUS A STATE PRIORITY INSTEAD OF A DEFAULT STARTING-POINT BY:

a. encouraging navigators, financial counselors, and other enrollment specialists to promote HIP Plus over HIP Basic

b. investing in personal outreach to conditionally-approved HIP members to explain PAC payments and the benefits of HIP Plus

5. SHIFT FROM QUARTERLY TO ANNUAL REVIEW OF INCOME ELIGIBILITY FOR HIP, WITH ONE YEAR OF HIP COVERAGE GUARANTEED:

a. allow members to submit life-change updates, including reduced income due to seasonal and temporary work or job losses, that lowers PAC amount; PAC could still rise with income changes

b. alternatively, continue quarterly review but average income over four quarters, except in cases when a life-change makes someone newly eligible for HIP coverage

6. OVERHAUL MEDICAID TRANSPORTATION SYSTEM TO:

a. ensure reliable, secure rides for patients and their family members

b. inform patients of guaranteed pick-up and return times

c. allow payment for transportation by private ride-sharing drivers and partnering community organizations

7. FSSA AND MCES STRENGTHEN PERSONAL ASSISTANCE FOR HIP APPLICANTS AND MEMBERS THROUGH:

a. investment in case managers, community health workers, or personal coaches to support high-utilization HIP members to shift toward better care continuity, disease management, and coordinated services

b. responsive relationships with certified navigators, financial counselors, and other enrollment specialists

c. responsive relationships with support professionals who assist people with HIP enrollment and utilization, including community health workers, care coordinators, social workers, recovery coaches, homeless advocates, and re-entry partners

8. FSSA AND MCES CREATE STRATEGIC PARTNERSHIPS WITH COMMUNITY AND FAITH ORGANIZATIONS TO:

a. build relationships with HIP-eligible people to identify root causes of quality of life issues and to connect them to holistic resources

b. sponsor support groups for eligible neighbors and congregants applying for HIP, navigating common program challenges and health conditions, and sharing health journeys

c. host knowledgeable HIP members to serve as community ambassadors in shelters, neighborhoods, congregations, or other locations with high HIP-eligibility

9. FSSA PARTNER WITH CORPORATE, NONPROFIT, COMMUNITY, AND FAITH ORGANIZATIONS ON A STATEWIDE CAMPAIGN TO COLLECT DONATIONS TO PAY PAC FOR HIP PLUS MEMBERS:

a. MCEs would facilitate these payments from intermediary nonprofits around the state

b. priority would be given to HIP Basic members, people eligible for but not enrolled in HIP, and current HIP Plus members earning 100% FPL or below

c. congregations could organize an annual Get HIP Sunday, Get HIP Saturday, Get HIP Friday and any other special day fundraising campaign

10. DEVELOP CLEAR INFOGRAPHICS IN DIALOGUE WITH FIRSTHAND HIP-USERS AND ORGANIZATIONS THAT HELP THEM APPLY, ENROLL, AND NAVIGATE HEALTH CARE:

a. map all of the steps in the HIP Process, including those taken by members and those taken by FSSA, its third-party partners, and MCEs

b. identify reasons why people lose HIP coverage and clear steps to avoid or remedy the losses

c. outline reasons why people miss out on HIP Plus—e.g., not paying PAC, not adjusting to higher PAC, not knowing how to submit PAC

d. clarify different eligibility requirements and program benefits for HIP and the state's other Medicaid plans

11. CONDUCT MIXED-METHODS RESEARCH WITH FIRSTHAND HIP USERS ON THESE QUESTIONS:

a. Why do African Americans have disproportionately lower HIP Plus rates? What lessons can be learned to help more African Americans and Hoosiers, in general, enroll in HIP Plus?

b. What lived realities account for annual coverage losses for 1 in 4 approved/enrolled HIP members? How can FSSA, DFR, call center, and MCE support be improved?

c. How do members utilize HIP Plus vs. HIP Basic coverage? How do health outcomes for both HIP Plus and HIP Basic members compare to Hoosiers on private, Medicare, and other state health plans?

d. How do applicants fare in enrolling in and maintaining HIP Plus when they receive personal assistance from a navigator, counselor, or other professional? How do the success rates compare to applicants assigned by a HIP broker?

e. How can FSSA and/or MCEs build strategic partnerships to expand personal assistance and build organizational relationships for HIP-eligible people?

FOCUS GROUP SOLUTION SPACES

Over the course of six participatory focus group sessions, 38 people who were either HIP members or were eligible for HIP contributed their perspectives, experiences, and priorities. This section is designed to synthesize the collected data to make recommendations for next steps which may include HIP program improvements, new or continuing interventions, or further research.

In reviewing the data, it is worth noting that none of the participant-identified solution spaces lend themselves to a one-size-fits-all resolution. For example, some participants were quite comfortable accessing and using the internet and showed preferences for technological solutions. Others, however, were more limited in both their access and interest in web-based solutions. Surprisingly, these differences did not match up with age, as some younger participants were most emphatic about the need for more personal support. In each of the areas that follow, more research is required to devise solutions that are both relevant and actionable for the users and implementers.

Personal Assistance

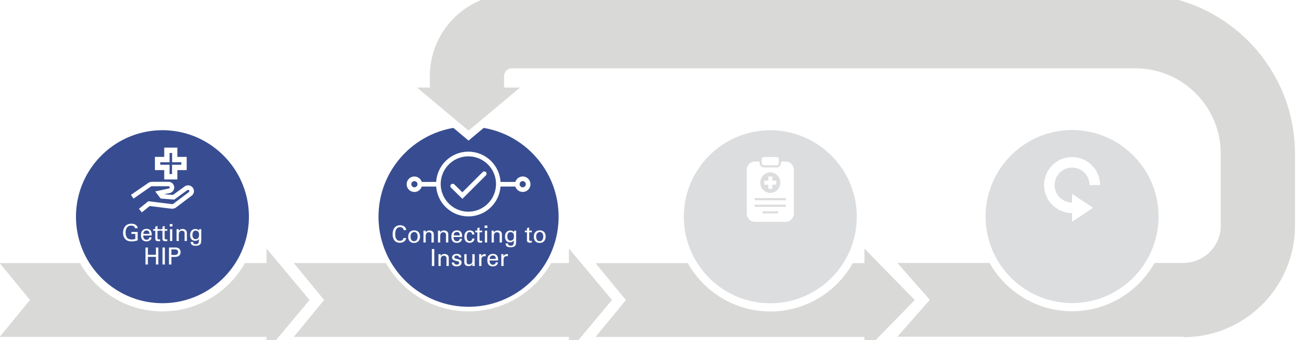
Perhaps the most wide-ranging theme in the collected data is the desire to have someone who understands the HIP/health care system who can provide personal and relevant assistance to users throughout the process. Study participants identified five different personal assistance roles. We introduce them here and indicate how direct personal assistance and coaching can be paired with improvements in the other two solution spaces: Improved Communication and Intentional Partnerships with Other Organizations.

Solution Features:

- Users are offered direct personal assistance (do not have to seek it out)
- Develop relationship with users; encourage ongoing follow-up
- Prepare users to advocate for themselves

WHO CAN PROVIDE ASSISTANCE?	WHAT IS THEIR EXPERTISE?
Insurance Navigators: Certified Navigators, Financial Counselors	Understand the HIP application, enrollment, and redetermination process; guide users through engaging with FSSA and insurers
Care Integrators: Case Managers, Community Health Workers, Social Workers	Take a holistic view of the user; connect users to answers regarding care; connect users to other support services
Community Partners: Service Coordinators, Program Directors, Wellness Ministries, Faith Community Nurses, Community Ambassadors	Build relationships with community organization clients, congregants, or neighbors; develop programs and offer support for health, wellness, and related service needs
Support Groups	Share experiences with others who have similar challenges with HIP, health conditions, or life circumstances
HIPAA Designee	Member can authorize anyone to receive communications and contact FSSA on their behalf

IMPROVED COMMUNICATION



1. GETTING HIP

KEY CHALLENGE:
Application is difficult to complete

SOLUTION FEATURES:

- Provide more direct assistance for those who are not computer savvy
- Simplify language to 6th grade level
- Provide clear guidelines and infographics on eligibility
- Allow applicants to upload digital copies of required documentation

Implementer(s): *FSSA*	**Personal Assistance:** *Insurance Navigators, Care Integrators*

KEY CHALLENGE:
Applicants are unsure about the status of their applications

SOLUTION FEATURES:

- Provide expected timeline and steps from application to conditional approval
- Create online tracking system (see Recommendation 1 above)
- Encourage applicants to authorize a HIPAA designee

Implementer(s): *FSSA*	**Personal Assistance:** *Insurance Navigators, Care Integrators, HIPAA Designee*

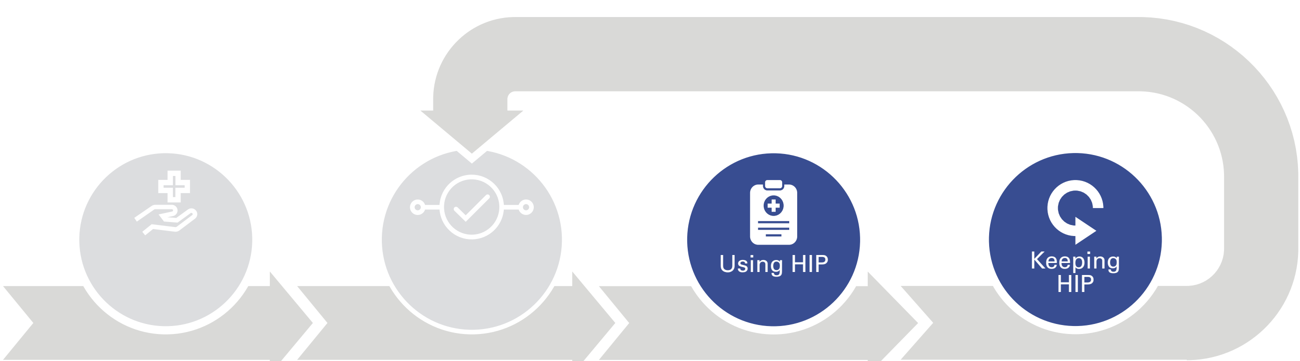
2. CONNECTING TO INSURERS

KEY CHALLENGE:
Unsure what is covered by plan, including medications, providers, procedures, transportation

SOLUTION FEATURES:

- Provide accessible coverage summaries of what is/is not covered
- Provide easier ways to find new providers
- Connect members to others on the same plan or with the same issues

Implementer(s): *Insurers*	**Personal Assistance:** *Insurance Navigators, Support Groups, Community Ambassadors*



3. USING HIP

KEY CHALLENGE:
Users feel they receive a "blizzard of information"

SOLUTION FEATURES:

- Prioritize communications when inaction threatens coverage
- Ask users what services they need and how they prefer to communicate
- Target communications based on user needs
- Use preferred communication channels to reinforce urgent reminders
- Provide access to FAQs for users

Implementer(s):
FSSA, Insurers, Providers

KEY CHALLENGE:
Users cannot easily access their member information

SOLUTION FEATURES:

- Provide access to updated personal accounts – coverage status, account balances, Gateway to Work reporting, outstanding issues

Implementer(s):
FSSA, Call Center, Insurers

Personal Assistance:
Insurance Navigators, Care Integrators, HIPAA Designee

4. KEEPING HIP

KEY CHALLENGE:
Users receive conflicting information from different FSSA, call center, and insurer employees

SOLUTION FEATURES:

- Make sure all communicators are working from the same information
- If employee does not have final authority, directly refer member elsewhere

Implementer(s):
FSSA, Call Center, Insurers

Personal Assistance:
Insurance Navigators, Care Integrators, HIPAA Designee

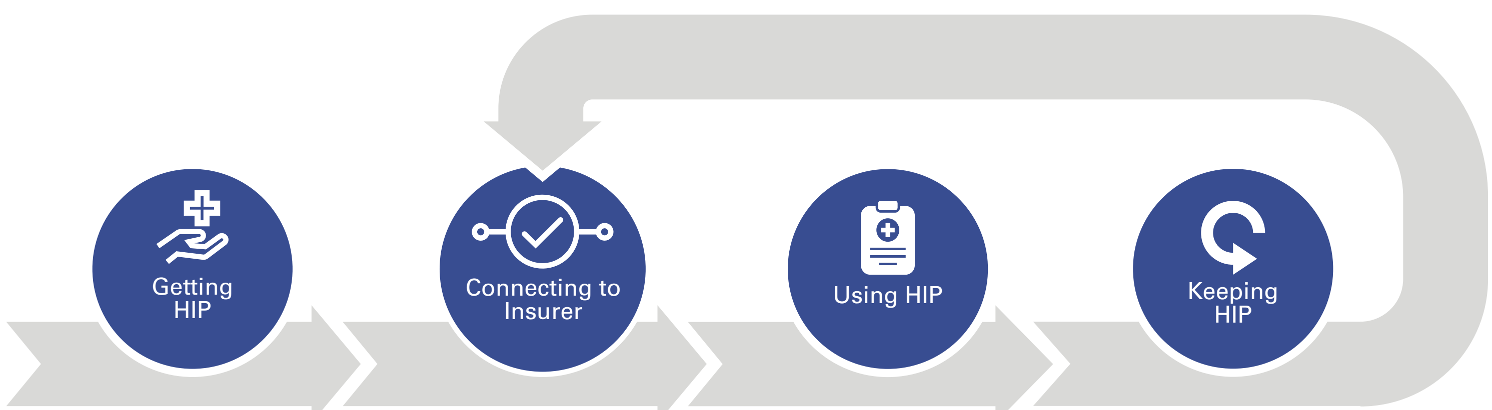
KEY CHALLENGE:
Users cannot easily access their member information

SOLUTION FEATURES:

- Provide access to updated personal accounts – coverage status, account balances, Gateway to Work reporting, outstanding issues

Implementer(s):
FSSA, Call Center, Insurers

Personal Assistance:
Insurance Navigators, Care Integrators, HIPAA Designee



ALL STEPS (1-4)

KEY CHALLENGE:
Members move physical addresses regularly

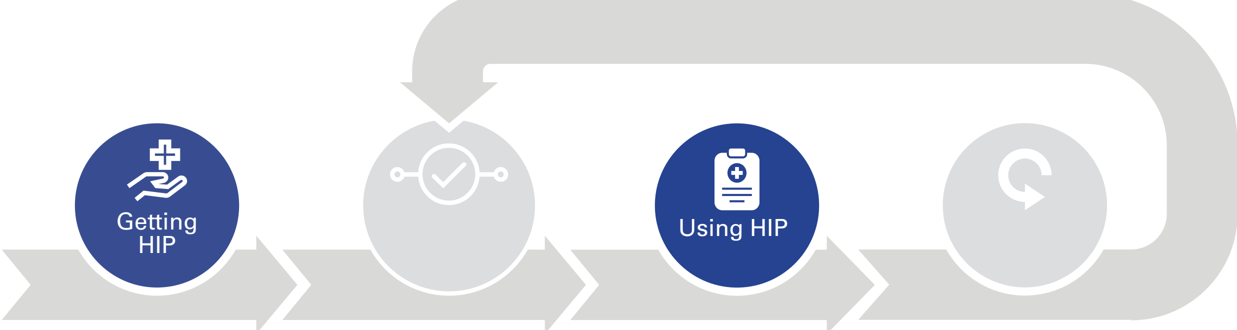
SOLUTION FEATURES:

- Send communications via multiple channels (phone, email, text message, website chat)
- Implement protocols to reach out to users as well as allowing them to initiate contact
- Encourage applicants to authorize a HIPAA designee

Implementer(s):
FSSA, Insurers

Personal Assistance:
HIPAA Designee

INTENTIONAL PARTNERSHIPS WITH COMMUNITY ORGANIZATIONS



1. GETTING HIP

KEY CHALLENGE:
Eligible users are not aware of program or where to find application

SOLUTION FEATURES:

- Do outreach at locations where eligible users are likely to be (congregations, groceries, libraries, barber shops, unemployment offices)
- Engage adept HIP users as ambassadors for their communities to get people to sign up
- Coordinate with service providers and wellness ministries in communities
- Sponsor HIP support groups through congregations and community organizations

Implementer(s): *FSSA, Insurers*

Personal Assistance: *Community Partners, Support Groups*

KEY CHALLENGE:
Many users are enrolled in multiple state safety net programs (for example, food stamps)

SOLUTION FEATURES:

- Coordinate services/share information between services so members do not need to duplicate efforts and documentation

Implementer(s): *FSSA*

Personal Assistance: *Care Coordinators, Service Coordinators*

3. USING HIP

KEY CHALLENGE:
Unreliable or expensive transportation

SOLUTION FEATURES:

- Ride sharing Model
  - Provide driver photo, contact information to patient
  - Provide GPS tracking on car for arrival time
  - Allow users to determine what time they are picked up
- Provide reimbursement for services other than Medicaid cabs (Uber/Lyft, non-profit organizations, fuel cards for family members to drive)
- Free bus passes
- Increase transportation benefit for high-use patients, e.g., methadone patients

Implementer(s): *FSSA, Insurers*

Personal Assistance: *Community Partners*

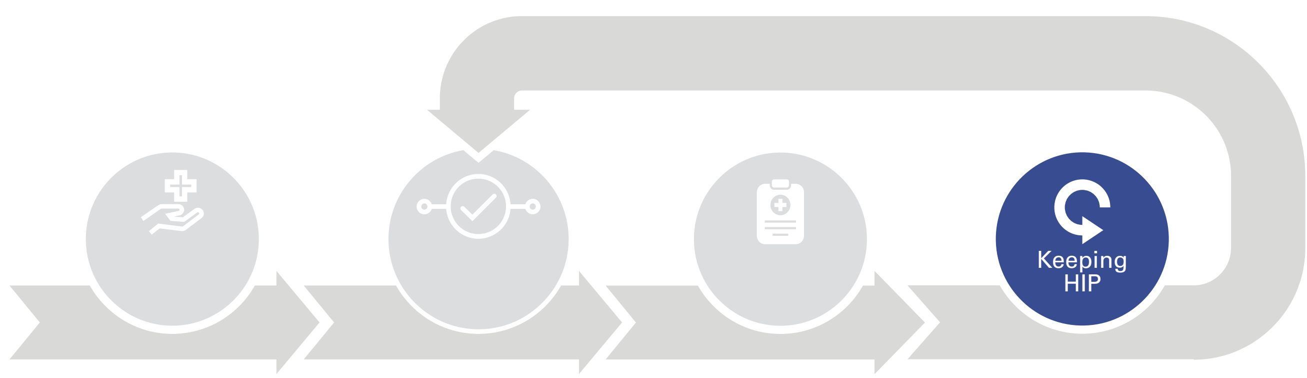
KEY CHALLENGE:
There are many social and economic barriers to accessing health care

SOLUTION FEATURES:

- Create data systems that track social determinants of poor health
- Connect patients directly to community-based service providers
- Provide access/directory of organizations that can help with:
  - Childcare
  - Education
  - Housing
  - Food
  - Employment
  - Other Social Determinants of Health

Implementer(s): *Insurers, Providers*

Personal Assistance: *Care Coordinators*



4. KEEPING HIP

KEY CHALLENGE:

Income becomes too high for HIP coverage, but not high enough to cover needs

SOLUTION FEATURES:

- Increase income limit for HIP coverage
- Approve HIP coverage for one year
- Partner with community groups to support people required to report under Gateway to Work
- Work with community partners to smooth transition to other health benefits
- Allow HIP members to spend residual POWER Account funds on federal Marketplace plans

Implementer(s):
Legislature, FSSA

Personal Assistance:
Program Directors, Service Coordinators

END NOTES

[1] State of Indiana, Healthy Indiana Plan Demonstration: Section 1115 Annual Report, Demonstration Year: 3 (2/1/17-1/31/18); submitted to CMS April 30, 2018, p. 1. Hereafter: Annual Report for Demonstration Year 3.

[2] The State of Indiana no longer calls the Medicaid expansion of the Healthy Indiana Plan HIP 2.0. We continue to use version number in order to distinguish HIP 2.0 from the original Healthy Indiana Plan (also called HIP original in this study).

[3] Kaiser Family Foundation, "Key Facts about the Uninsured Population" (Dec. 7, 2018); https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/

[4] This research was approved by the IUPUI Institutional Review Board study #1807428156.

[5] We thank Nikki Garner for transcribing the interviews and Shelby Elrod for her graphic design of this report. Videos were filmed and produced by Tom Corey for Shepherd Community Center and Garry Holland for First Baptist Church North Indianapolis. We thank them for their work.

[6] Mitchell Roob and Seema Verma, "Health Care Amidst Colliding Values," Health Affairs Blog (May 1, 2008), http://healthaffairs.org/blog/2008/05/01/indiana-health-care-reform-amidst-colliding-values/

[7] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 2.

[8] Natalie Angel, "HIP Presentation: Shepherd Community Center" (Jan. 24, 2019), slide 5.

[9] Robin Rudowitz, MaryBeth Musumeci, and Elizabeth Hinton, "Digging Into the Data: What Can We Learn from the State Evaluation of Healthy Indiana (HIP 2.0) Premiums" (Kaiser Family Foundation, March 2018), p. 1.

[10] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 28.

[11] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 2.

[12] Data reflects census tract 3512 where First Baptist Church North Indianapolis is located. Census tract data is an approximation of neighborhood data.

[13] Data reflects census tract 3551 where Shepherd Community Center is located. Census tract data is an approximation of neighborhood data.

[14] David M. Craig, Health Care as a Social Good: Religious Values and American Democracy (Georgetown University Press, 2014).

[15] Rudowitz, et al. "Digging Into the Data," p. 2.

[16] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. p. 17

[17] Kaiser Family Foundation, "Premium and Cost-Sharing Requirements for Selected Services for Medicaid Adults (Jan. 1, 2019); https://www.kff.org/health-reform/state-indicator/premium-and-cost-sharing-requirements-for-selected-services-for-medicaid-expansion-adults/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D#

[18] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 14.

[19] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 8.

[20] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 2.

[21] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 16.

[22] FSSA, "HIP Work Gateway to Work Program Update 2-25-19," slide 3; http://www.iccmhc.org/sites/default/files/webinars/Gateway%20to%20Work%20Program%20Update.pdf

[23] David R. Williams, "Health and Quality of Life Among African Americans," The State of Black America 2004, ed. Lee A. Daniels (New York: Urban League, 2004), p. 122-123.

[24] Robin Rudowitz, Rachel Garfield, and Elizabeth Hinton, "10 Things to Know about Medicaid: Setting the Facts Straight," (Kaiser Family Foundation, Mar. 2019), p. 1.

[25] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 1.

[26] Indiana HIP 2.0: Annual Report for Demonstration Year 3, p. 11.

[27] Natalie Angel, "HIP Presentation: Shepherd Community Center" (Jan. 24, 2019), slide 14.

[28] Harry J. Helman and Samantha Artiga, "Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity" (Kaiser Family Foundation, Nov. 2015), p. 3.