



COLLABORATING FOR CONSUMERS

HOW ASSISTERS AND ADVOCATES
CAN INFORM POLICY

A PUBLICATION BY



GEORGIANS FOR A
HEALTHY FUTURE

THE VOICE FOR GEORGIA HEALTH CARE CONSUMERS



In August 2016, Georgians for a Healthy Future convened consumer and patient advocates, health insurance enrollment assisters, and direct service providers for a half-day summit to discuss opportunities for collaboration to better reach shared goals of

increasing coverage and access to care in Georgia. Approximately one hundred people participated in the convening, which included separate breakout sessions for enrollment assisters and for advocates as well as two panel discussions featuring policy experts and leaders from the various sectors represented.

This paper presents several opportunities for advocates and assisters to work together to improve coverage and access to care for health care consumers in Georgia. Some of these ideas were proposed and discussed at the convening, while others were developed through research and individual interviews conducted by Georgians for a Healthy Future. It should be noted that, while the policy opportunities discussed below are described in terms of assister-advocate collaboration, they may also apply to opportunities for collaboration between a range of service providers who help consumers and advocates.

The Opportunity

Health advocates and enrollment assisters both work for consumers. Assisters help to ensure consumers have the information and assistance they need to access coverage and care; advocates work to ensure that the health system meets the needs of consumers. Over the past three years, nearly half a million Georgians have newly enrolled in health insurance, many with the help of enrollment assisters. By communicating with each other about trends in consumer experiences, best practices that can be scaled up, systemic challenges and barriers faced by consumers, and policy opportunities that can address these challenges, assisters and advocates can create a feedback loop that informs policy and benefits consumers. Despite these opportunities for collaboration, there remains some space between Georgia’s assister and advocate communities. This paper is intended to serve as a roadmap for collaboration between these two communities.



Enrollment Assister

Health insurance navigator and certified application counselor organizations provide free, unbiased help to consumers in every region of the state who need assistance with the health insurance enrollment process. In Georgia, both navigators and certified application counselors must complete federal and state training and be certified to provide assistance to consumers. The term “enrollment assister” can refer either to a health insurance navigator or a certified application counselor.

2P: PATTERNS AND PARTNERSHIPS



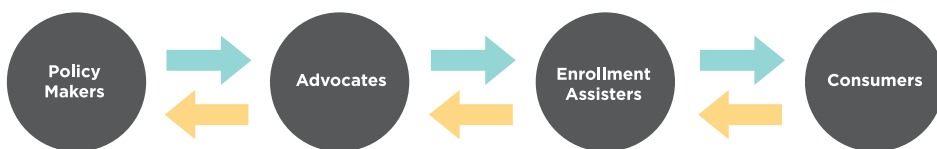
During the August convening, enrollment assisters and direct service providers participated in a case study exercise to think through how to better identify patterns and form partnerships with groups that can apply those patterns to the policy arena. Participating assisters determined that knowing what to refer, when to refer, and to whom to refer would allow them to serve consumers beyond their capacity.

During enrollment appointments or other encounters, consumers necessarily provide individual information to their enrollment assister about their health status, problems that they have had with their coverage, affordability concerns, and more. Assisters, consciously or not, aggregate this information and feedback so that they can intuitively identify themes and trends among their consumers which may highlight barriers to coverage or care. When advocates are made aware of these trends by assisters, advocates can work to identify what systemic changes are needed and build a strategy for change accordingly. When advocates are successful in their efforts and there is a resulting policy change that will affect consumers, advocates are then responsible for supporting enrollers. Advocates must educate assisters about the changes so that assisters can adjust their enrollment practices, or community outreach and education to match the new policy and accommodate the consumers who are affected.

Enrollment assisters play a critical role in connecting millions of people to health coverage. They work tirelessly to ensure that everyone who applies for coverage has the right information to choose the plan that's best for them, and to ensure that consumers are able to stay covered and get the health care they need. Assisters are also trusted voices in the communities they serve.

– Families USA, Public Policy for Assisters Guide

Advocates and enrollment assisters can also partner to directly serve their constituents. Consumers seek out assisters to answer questions about or to enroll in health care coverage, but these same consumers may need other resources and supports. Assisters are often not equipped to provide supports like transportation, disease-specific information & assistance, or legal advocacy; however, many advocacy organizations have these capabilities and can work with consumers to fulfill their needs beyond the scope of what enrollment assisters can deliver. Advocates may also reciprocate with referrals of their own, by identifying constituents who remain uninsured or need enrollment or post-enrollment assistance. These reciprocal relationships can result in an assister who develops an expertise in the health needs of certain populations (e.g. refugees, people living with HIV/AIDS, diabetics), and is better able to assist consumers in choosing coverage that will serve their health needs. Through assister-advocate partnerships, the spectrum of consumer needs can be met more completely.



See complete diagram on page 14.

Section 1557 of the Affordable Care Act

Released in May 2016, the final rule for Section 1557 prohibits discrimination based on race, color, national origin, sex, age or disability in certain health plans (including Market-place plans), by certain health care providers, and in other circumstances. Significantly, this rule is the first time that health care discrimination based on sex is disallowed by the federal government. This new rule has the potential to reduce health disparities experienced by women (especially women of color), transgender individuals, and those who identify as gay, lesbian, bisexual, or otherwise. Because this rule is so new, it is especially important for assisters and advocates to work together to identify successes and failures so consumers experience the full benefits of protection under Section 1557.

Policy Opportunities

Discussions with advocates and assisters have resulted in the identification of several policy opportunities that are ripe for assister-advocate partnerships. These issues contribute greatly to the experience that Georgia's consumers have or will have with their health care coverage and the health care system. It is in their interest that advocates and assisters work together to ensure consumers' interests are addressed.



COSTS AND BENEFIT DESIGN IN HEALTH PLANS

While health care costs have grown more slowly in recent years, plans are shifting more costs to consumers through higher deductibles and out-of-pocket costs. That means that despite many more people buying health coverage, there are some that cannot afford to access the care that should come with coverage. Two opportunities exist for advocate-assister partnerships to influence the costs of coverage.

The first is rate review, an annual process during which insurance companies submit their proposed plan rates for the coming year to be reviewed by state and federal regulators. Included in the review process is the opportunity for public comment when advocates and other interested stakeholders can submit comments to the Georgia Department of Insurance (DOI) regarding their concerns about proposed rate changes. Georgia's DOI in turn must respond to the proposed changes, requesting further adjustments if proposed rates are not reasonable or are insufficiently justified. Assister input can help to inform and strengthen public comments made by advocates. When a strong case against rate increases is made the result may be lower costs of coverage, which consumers consistently express is their biggest concern when purchasing coverage.

The second opportunity to influence costs is in the identification of discriminatory or unclear practices in cost-sharing or service coverage. Because assisters are often very familiar with the details of the various health plans available in their service areas, they may be able to identify trends in drug tiering or cost-sharing for certain services that disproportionately affect a population of people (ex: people diagnosed with hemophilia or people who identify as transgender). If they share this information with advocates, then advocates can work with the DOI and insurers to resolve the discriminatory practices. The recently issued ACA Section 1557 rules on non-discrimination provide a timely example on the importance of this kind of work and partnership.

ASSISTER BREAKOUT SESSION: CASE STUDY

During the assister breakout session at the August convening, a case study focused on LGBTQ Georgians who may face discrimination and how new non-discrimination rules under Section 1557 of the Affordable Care Act may apply. Assisters worked together to develop some acronyms to help them identify potential cases of discrimination for referral. These acronyms are:

NOC-DARS:

**National Origin, Color,
Disability, Age,
Race and Sex.**

NOC-DARS represents the areas in which discrimination is prohibited in health care under 1557.

SILVER:

S: State where the event took place
I: Institution involved
L: List details
V: Violation Type
E: Evidence
R: Representative Involved

SILVER represents the information that consumers may need to provide to help document and report cases of potential discrimination in health care.



Enrollment assister Vincent Spann led the group in developing these acronyms during the breakout session.

In addition to costs, the structure of Marketplace health plans is an important issue facing consumers. The Center for Medicaid and Medicare Services' (CMS) annual plan certification review process provides an opportunity for assisters and advocates to partner to influence health plan structure. This process determines if Marketplace health plans adhere to the state's benchmark health plan, which defines the minimum essential health benefit (EHB) standards as well as other federal requirements regarding EHB. The benchmark plan is used by insurers to build the list of services that will be covered under their own QHPs. Advocates may analyze the benchmark plan to identify any discriminatory structures and opportunities to improve or clarify the coverage of certain services. For example, in 2015 two advocacy organizations filed a complaint that several insurers in Florida violated the discriminatory benefit standard for EHBs by placing all HIV medications (including generics) in the highest cost-sharing tier. In these types of situations, it is helpful if advocates have some substantiating consumer data on which to build their comments or complaints. Assisters can help advocates build their case by validating the suggested changes with documented consumer experiences to compel regulators to enforce policies.¹



NETWORK ADEQUACY

Network adequacy serves as a critical link between having health insurance and accessing health care services. When consumers enroll in a health insurance plan, they gain access to a network of medical providers who should be able to deliver all of the health care services included within the plan's benefit package.

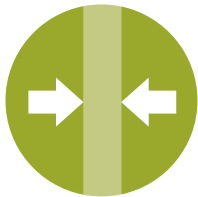
While network adequacy is not a new concept, it has a new urgency in light of the sheer number of newly insured Georgians enrolled in individual plans; the move on the part of insurance companies toward narrow networks and tiered networks, which limit the number of providers that plan enrollees can access; new federal standards; and a new model act from the National Association of Insurance Commissioners (NAIC) that provides updated guidance for states. Georgia's health advocates are already working to encourage state policymakers to adopt quantifiable, enforceable, modern network adequacy standards, similar to what is laid out in the NAIC model act released in the fall of 2015.

Around the same time, the recipients of a new round of federal funding for enrollment assistance were announced. That funding, which extends from 2015 to 2018, came with the requirement that assisters place an increased emphasis on the post-enrollment needs of consumers. These needs include finding an in-network health care provider, education on how to use health coverage effectively, and assistance with the complaints and appeals

PROVIDER DIRECTORY IMPROVEMENT LEGISLATION

When helping consumers find a health care provider, assisters often use or refer consumers to the plans' provider directories. Local assisters repeatedly found these directories to be inaccurate and incomplete. GHF received this feedback through informal partner relationships and through formal debrief sessions after open enrollment periods. GHF used this information to craft legislation that improves the accuracy and usability of provider directories and worked with the legislature and advocacy partners to get it passed into law. Now that the legislation has been adopted, GHF will work with the Department of Insurance to craft regulations so that the new law can be implemented and enforced effectively. GHF will need to educate assisters about several of the provisions of the new legislation as they directly affect consumers. For example, assisters will need to be informed about the new complaint processes so that they can refer consumers to a portal to report provider directory issues. Additionally, the legislation requires insurers to honor provider directory inaccuracies and charge consumers to pay only the in-network cost-sharing, if a consumer relies on an inaccurate directory and, as a result, receives care out-of-network. These, along with other provisions, will be important for assisters to understand as consumers may come to them if they are surprised by an unexpected out-of-network bill.

process through the Marketplace and insurers. Through this post-enrollment work, many assisters will gain an understanding of how the issue of network adequacy is impacting their consumers, and this information will be very important in the on-going policy discussions of network adequacy. Feedback from assisters may vary significantly depending on an assister's location in an urban or rural community, the types of providers available in an area, or even the number of health plans offered in the region. Documented consumer experiences and trends, as communicated by assisters, will be critical for advocates and policy makers, especially as they seek to define network adequacy standards that will be applied statewide across thousands of differing communities.



COVERAGE GAP

Georgia has yet to close the coverage gap created by a 2012 Supreme Court decision that leaves hundreds of thousands of low-income Georgians without health coverage because they do not qualify for Medicaid and cannot get financial assistance to purchase health care coverage on the Marketplace. Many of those in the coverage gap come to enrollment assisters to try to enroll in health insurance only to find out that they do not qualify for any type of coverage. In fact, Georgia's enrollment assisters have repeatedly expressed to advocates that this is the biggest barrier to enrollment that their consumers face. While enrollment assisters may be unable to advocate publicly for Georgia to close its coverage gap by expanding Medicaid, they still have a very important role to play in the debate over this policy.

POLICY BREAKOUT SESSION



During the policy breakout session at the August convening, advocates broke into three groups to discuss the most important advocacy issue they could take on in 2017 in the areas of affordability, access to care, and the uninsured. All three groups identified the same issue as their highest priority: closing the coverage gap.

Consumer stories from people who fall in the gap are consistently among the best tools that advocates have in the fight to close the gap. Stories from real Georgians help to illustrate to community leaders, the media, and policymakers who is in the gap, how this policy decision impacts their lives, and why it's important to address this issue now. It also provides the consumers with a sense of empowerment; rather than being left with no health insurance and no options, they can tell their story and be part of an effort to fix the problem. Assisters interact with people in the coverage gap regularly through their community outreach and enrollment work. One of the most important things assisters can do is to connect people in the gap with advocates. Advocates can then work with those Georgians to connect them to free health care and to empower them to share their story so that they can advocate for themselves. Advocates can facilitate story collection by working with assister organizations to create HIPPA-compliant waiver forms so that consumer information can be shared between partners in a way that protects the consumer and the assister.

In the coming years, the effort to close the Georgia's coverage gap will be successful and health care coverage will be extended to low-income Georgians. At that point, it will be imperative that assisters and advocates work together to reach the hundreds of thousands of people who are newly eligible for coverage. Depending on how Georgia crafts its coverage gap solution, consumers may be enrolling in private coverage through the Marketplace, public coverage through Medicaid, or a uniquely-Georgia coverage option. Enrollment assisters will be some of the primary messengers to let people know that they may newly qualify for coverage and to educate them on how to enroll. Advocates will need to work with assisters to make sure they understand who may or may not qualify, how enrollment may work, and what consumers need to do to use their coverage and stay enrolled. Strong partnerships will be important so that timely, accurate information gets to consumers across the state.



CONSUMER ASSISTANCE

Consumer assistance is a foundational activity for enrollment assisters and an important part of the work of advocates as well. Neither can provide everything a consumer needs, but partnerships and referrals can help provide more complete consumer support. In this way, assisters and advocates make natural partners. Aside from direct

consumer assistance, there are additional opportunities in the consumer assistance space for assister-advocate partnerships.

In the 2016-2017 open enrollment period (Open Enrollment 4), five states with federally facilitated marketplaces will be pilot testing a new quality rating system (QRS) for health plans offered in their states. The QRS are meant to provide consumers with information about prospective health plans' performance on key quality and consumer satisfaction metrics. Georgia is not one of the pilot sites; however, advocates should spend the year learning from the pilot states by talking to other state advocates and keeping the Georgia Department of Insurance (DOI) informed of these efforts. Further, assisters should share with assisters the information they have about how QRS have worked elsewhere and, when it is rolled out in Georgia, help assisters tailor outreach and education tools for consumers to reflect the new QRS. This collaboration should result in a rating system that is easily useable and understandable by consumers, and provides them with the information they need to make enrollment decisions. Assisters and advocates should continue to share feedback with each other after the implementation of the QRS as the system will need to be improved and refined over time to reflect consumer needs and changes in technology and health plan structure.

To further assist consumers, advocates and assisters may work together to promote the implementation of a state Consumer Assistance Program (CAP). State CAPs provide a wide range of consumer services, including assisting consumers with filing appeals of claim denials or complaints against health plan practices; educating consumers about their rights in getting and keeping health insurance; tracking consumer complaints to help identify recurring problems and strengthen oversight; and helping consumers resolve problems with obtaining premium tax credits.

Georgia had a CAP operated by the DOI until 2013, when funding was discontinued. Re-establishing a CAP would be valuable to Georgia consumers, provide assisters with a partner within the DOI, and benefit advocates by providing important statewide data about the problems that consumers are experiencing with their coverage. Assisters can help in the effort to establish a Georgia CAP by providing data to advocates of how many of their consumers need complex post-enrollment assistance, and trends about what types of post-enrollment assistance are needed.

Steps to collaboration in Georgia

It is clear that there are a myriad of opportunities for advocates and assisters to partner for the benefit of Georgia's consumers. In order to collaborate successfully, partnerships must be developed and both parties must actively opt to participate in the partnership. Enrollment assisters and advocates must each play a role in facilitating these collaborations.

It is evident that enrollment assisters' relationships to their communities and to individual consumers are a key tool that can be leveraged for policy change. One way their relationships can be utilized is the collection of individual stories that illustrate trends in consumer experiences, like difficulty finding a provider, falling in the coverage gap, or discriminatory coverage within a health plan. Assisters can partner with advocates to collect those stories through a variety of mechanisms. This may include a "warm" hand-off when an assister contacts an advocate on a consumer's behalf to introduce them and begin the conversation; collecting a consumer's contact information with a waiver that allows them to share the information with an advocate partner; or collecting the consumer's full story (and waiver) to share with advocates.



"We often sit at advocacy tables, and we invite you to sit at our tables too. I encourage advocates to seek out opportunities to participate in the activities of direct service organizations by participating in advisory committees and working with us on story collection."

Jemea Dorsey
CEO of the Center for Black Women's Wellness

The innumerable individual interactions that assisters have with consumers can also become a powerful source of data if collected in a concerted way. Many assisters must report consumer stories as part of their regular reporting, along with more standard metrics like number of consumers assisted or enrolled. Assisters can record these consumer stories in spreadsheets or databases in a way that makes it easy to analyze the stories for recurring themes. This data can be easily sorted and reviewed before debriefs or partner meetings to inform the discussion and highlight issues that may be surfacing. If assisters are already recording data like this, assister organizations can aggregate it for an even wider perspective on consumer experiences. This data aggregation would be especially significant if it were

A PARTNERSHIP FOR IMPROVED HIV CARE AND ACCESS TO MEDICATIONS

Enrollment assisters from The Health Initiative (HI) work on-site at AIDS Service Organizations (ASOs) to ensure people living with HIV & AIDS (PLWHA) have the resources they need to access health care and coverage. This includes enrollment assistance for PLWHA, among other services. This relationship provides HI with on-the-ground information about consumers' experiences related to managing their HIV/AIDS diagnoses.

When HI identifies a problem, like specialty tier pricing for HIV medications, assisters inform advocates at Georgia Equality (GE), with whom they share office space. GE then works with governmental entities to identify ways to educate consumers about their options for getting those medications at an affordable price.

Oppositely, when GE received information at a policy meeting about problems for consumers trying to access Pre-exposure prophylaxis (PrEP) medications to prevent the transmission of HIV, the advocates asked the HI assisters if this was bearing out among consumers at the ASO. This real-time information provided important feedback to GE about the extent of the problem.

periodically reported to stakeholders like state advocates and the Georgia Department of Insurance. State advocates can then pass relevant information on to federal advocates (like In the Loop) and the U.S. Department of Health and Human Services so that it can be addressed at the most appropriate level. Both the collective data of consumer experiences by assister organizations and individual consumer stories from assisters provide important information that can help to influence the policy conversations on relevant issues.

Advocates also need to consider how they can be good partners and reciprocate the work of assisters. One way to do that is to establish relationships with assisters through consumer referrals. Advocates may want to train a number of enrollers on the characteristics of the people that they represent, their health needs, and other information that may be helpful in the enrollment process. In this way, the assisters can better help consumers, and advocates can feel confident in their referrals. Advocates can also help assisters by partnering with them to develop consumer education tools. Assisters know what kind of educational resources, like fact sheets or videos, consumers need, but often do not have the time or resources to create them on their own. With input from assisters, advocates can create these resources for use by assisters and consumers. Georgians for a Healthy Future did this with the development of an enrollment toolkit, which included fact sheets for every stage of enrollment and post-enrollment, and an interactive post-enrollment workbook for use by consumers who are new to health insurance. GHF has distributed these resources to enrollment assisters for their use with consumers and provides free access to them through the Georgia Enrollment Assister Resource (GEAR) webpage.

Advocates can build on their partnerships with assisters, by specifically soliciting assister involvement and feedback in policy matters. Advocates can do this by inviting assisters to take part in relevant coalitions, policy forums, and other meetings. Having assisters at the table for these conversations will facilitate opportunities for assister feedback on policy issues, help both parties develop a shared language and perspectives, and build trusting relationships between them. Along the same lines, advocates should specifically solicit assister feedback when determining a policy agenda, strategy for a policy change, submitting public comments to a government agency, or other relevant effort. The on-the-ground information and consumer experiences that assisters provide may provide critical information that helps to shape recommendations and policy, ultimately strengthening the outcome of the effort and benefiting consumers.

Conclusion

The health insurance and health care systems are increasingly complex, and consumers need help. They need help making sense of their options and rights as consumers, and they deserve to have their voices heard as policy decisions are made that impact their health and access to care. Strengthening partnerships between organizations that specialize in policy advocacy and those that directly serve consumers each and every day can help ensure that consumers have a voice and that our health system works for them.

REFERENCES/RESOURCES

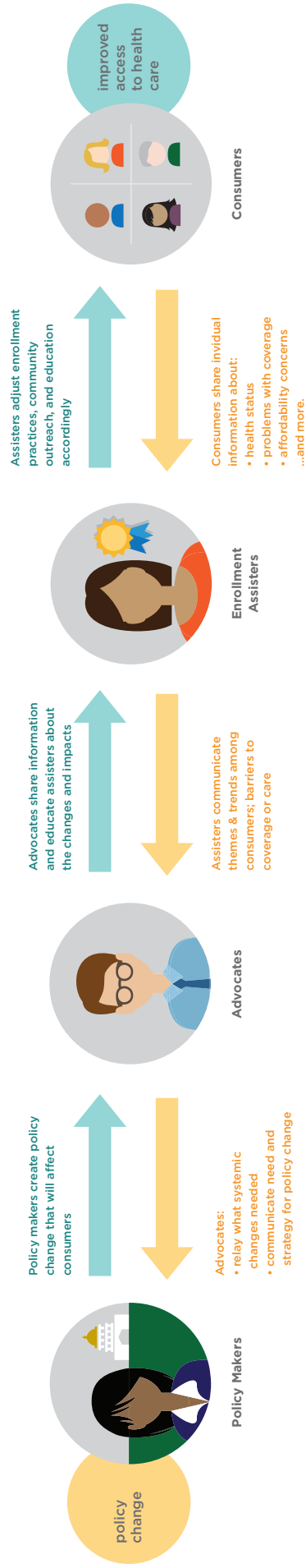
Families USA, Public Policy Toolkit for Enrollment Assistors: http://familiesusa.org/sites/default/files/enrollment-assister-toolkit/docs/NAV_Enrollment%20Assisters%20Toolkit_web_full.pdf

Network adequacy report, GHF

CAP program report: <https://www.cms.gov/CCIIO/Resources/Files/Downloads/csg-cap-summary-white-paper.pdf>

¹ The National Health Law Program and the AIDS Institute. (2015, January 19). Letter to HHS Office of Civil Rights on pending HIV discrimination complaint. Retrieved from <http://www.healthlaw.org/publications/browse-all-publications/Letter-to-HHSOfficeofCivilRights#.V3Ku-WgrKUk>

SYSTEM IMPROVEMENTS & POLICY CHANGE



INFORMATION & RECOMMENDATIONS



100 Edgewood Avenue NE, Suite 1015
Atlanta, Georgia 30303

TEL 404 567 5016

FAX 404 935 9885

EMAIL info@healthyfuturega.org

healthyfuturega.org