

## **Health Systems Analysis Data Sources**

Data for the Health Systems Analysis was compiled from a wide variety of local, state, and federal resources listing breast health resources including:

- The Food and Drug Administration's list of certified mammography centers
- The National Association of County and City Health Officials' list of health departments
- Lists of Health Centers and Free Clinics
- Lists of specially accredited or certified centers

Komen Atlanta staff also used existing relationships with grantees and the local breast cancer community to identify facilities in addition to conducting internet searches to locate any services and resources that may have previously been unknown to Komen Atlanta. Once facilities and organizations were located, the services provided at each location in the target counties were verified either by the organization's website or a phone call to the organization.

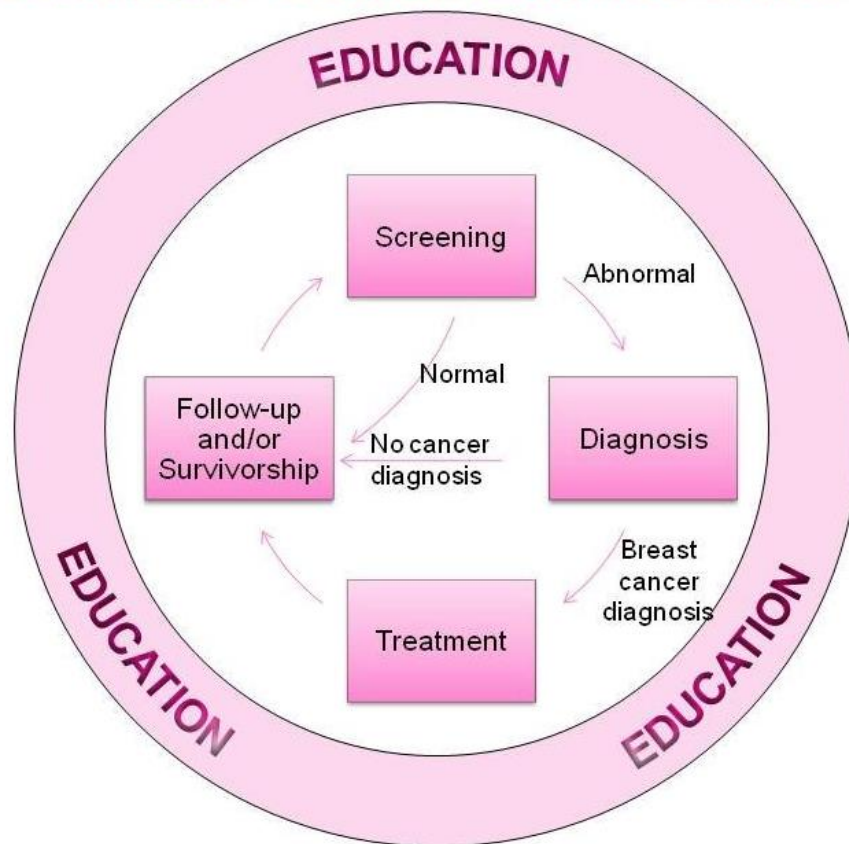
Komen Atlanta staff and Community Profile Committee members reviewed the resources for each county by assembling the information collected into a spreadsheet with a separate worksheet for each target community. Organizations were listed in the county where they operate, regardless of the counties from which their constituents come. Collecting all of the services providers for a target area on one sheet allowed Komen Atlanta staff to view the strengths and weaknesses of each area with regards to the availability of services in the area.

In addition to assessing the structure and availability of services in the target communities, Komen Atlanta also conducted an assessment of local, state, and federal policies that impact access to breast health care in the service area. The Public Policy Analysis follows the Health Systems Analysis and helps to provide a more thorough explanation of barriers to education, screening, and care in the target communities.

## **Health Systems Overview**

The Continuum of Breast Health Care

# Breast Cancer Continuum of Care (COC)



The Breast Cancer Continuum of Care (CoC) is a model that shows how a person typically moves through the health care system for breast care. An individual would ideally move through the CoC quickly and seamlessly, receiving timely, quality care in order to have the best outcomes. Education can play an important role throughout the entire CoC. While a person may enter the continuum at any point, ideally, a person would enter the CoC by getting screened for breast cancer – with a clinical breast exam or a screening mammogram. If the screening test results are normal, she would loop back into follow-up care, where she would get another screening exam at the recommended interval. Education plays a role in both providing education to encourage people to get screened and reinforcing the need to continue to get screened routinely thereafter.

If a screening exam resulted in abnormal results, diagnostic tests would be needed, possibly several, to determine if the abnormal finding is in fact breast cancer. These tests might include a diagnostic mammogram, breast ultrasound or biopsy. If the tests were negative (or benign) and breast cancer was not found, she would go into the follow-up loop, and return for screening at the recommended interval. The recommended intervals may range from three to six months for some people to 12 months for most. Education plays a role in communicating the importance of proactively getting test results, keeping follow-up appointments and understanding what it all means. Education can empower individuals and help manage anxiety and fear.

If breast cancer is diagnosed, she would proceed to treatment. Education can cover such topics as treatment options, how a pathology reports determines the best options for treatment, understanding side effects and how to manage them, and helping to formulate questions a person may have for her providers.

For some breast cancer patients, treatment may last a few months and for others, it may last years. While the CoC model shows that follow up and survivorship come after treatment ends, they actually may occur at the same time. Follow up and survivorship may include things like navigating insurance issues, locating financial assistance, symptom management, such as pain, fatigue, sexual issues, bone health, etc. Education may address topics such as making healthy lifestyle choices, long term effects of treatment, managing side effects, the importance of follow-up appointments and communication with their providers. Most people will return to screening at a recommended interval after treatment ends, or for some, during treatment (such as those taking long term hormone therapy).

There are often delays in moving from one point of the continuum to another – at the point of follow-up of abnormal screening exam results, starting treatment, and completing treatment – that can all contribute to poorer outcomes. There are also many reasons why a person does not enter or continue in the breast cancer CoC. These barriers can include things such as lack of transportation, system issues including long waits for appointments and inconvenient clinic hours, language barriers, fear, and lack of information - or the wrong information (myths and misconceptions). Education can address some of these barriers and help a person progress through the CoC more quickly.

## **Mission Related Partnerships and Opportunities**

### **Cherokee County**

Komen Atlanta's primary partners in Cherokee County are Northside Hospital and WellStar hospitals along with their affiliated offices. Northside is a longtime Komen Atlanta grantee and serving uninsured and underinsured people throughout the service area. Northside's recent expansion into Cherokee County provides more breast health resources in the area than were previously available, but Northside's free and low-cost screening resources are limited given the demand for their services. WellStar also receives Komen Atlanta screening and diagnostic funding, though the majority of their funds are spent screening individuals in other counties.

The county health department is also an important point of access in the county, but the health department primarily screens women age 50-64 through clinical breast exams and refers out for mammograms when necessary. Women who do not fall within these guidelines or who are undocumented immigrants may not be able to be screened within the county if they cannot pay for services. Northside and WellStar hospitals are the primary providers of treatment and support services for breast cancer patients, but individuals may need to drive to neighboring counties for ancillary services. Survivorship resources and non-medical support including legal aid, financial assistance, and counseling are limited in the area.

In order to better meet the needs of individuals in Cherokee County, Komen Atlanta needs to seek out relationships with the county health department and community clinics in the area – particularly those that can serve Spanish-speaking individuals. Throughout the service area, Komen Atlanta will also begin to invest in survivorship programs given their scarcity in and for the target populations identified.

### Clayton County

Clayton County has one health department office that provides clinical breast exams and mammography referrals and one hospital that provides for the full continuum of breast health care, and they are supplemented by a few community health centers and free clinics that can provide clinical breast exams and referrals. The county is geographically close to many providers in Fulton County and the City of Atlanta, but there is no public transportation in Clayton County, and transportation assistance is scarce.

Komen Atlanta partners with the Clayton County Health Department and the Women's Center at Spivey Station to pay for breast screenings, diagnostics, and lymphedema care. Komen Atlanta grants increase the number of individuals who can be screened through the programs, but additional partnerships are needed to reduce transportation and other economic barriers to screening. Mobile mammography is one potential solution to this challenge, but there are no mobile mammography providers serving the area regularly at this time.

### DeKalb County

DeKalb County is metro Atlanta's second most populous county. It is home to Emory University Hospital, a large private research institution and Georgia's only NCI designated cancer center, and DeKalb Medical Center, a public hospital. Grady Hospital, the metro area's largest indigent care facility, serves DeKalb County residents but is located in neighboring Fulton County. These hospitals provide services along the entire continuum of breast health care. Several free clinics and community health centers are also located in DeKalb County, but these clinics typically perform clinical breast exams only and provide referrals to the hospitals for additional services.

Though there are a number of high quality breast health services in DeKalb County, the resources are not enough to meet the needs of the entire population, especially the uninsured and immigrant populations in the northern part of the county. This is particularly true since the closing of DeKalb Medical Foundation's Wellness on Wheels (WoW) in 2013. WoW formerly provided mobile mammography services for a large portion of the uninsured and underinsured population in the area. There is no other organization providing such a high volume of free or low-cost screenings in the county, so people must cross into a neighboring county for services. Because of a large recent immigrant population in the county, language is also a significant barrier to education, screening, diagnostics, and treatment for much of the population.

Since the closing of WoW, Komen Atlanta does not have a large volume breast screening partner in DeKalb County. Komen Atlanta partners with and provides grants to a number of smaller organizations who provide clinical breast exams and refer out for mammography, but there are not sufficient hospitals and screening facilities conducting low cost

mammograms in the county to serve all of the population in need. Komen Atlanta should seek out partners to fill this need and continue to invest in culturally competent breast health education and services for the diverse population in the county.

### Fulton County

Fulton County has the largest population in the metro Atlanta area and is home to branches of five hospital systems, including the region's largest public hospital. These hospitals provide the majority of free and low cost mammography, diagnostics, and treatment not only for individuals who enter the CoC via the hospitals but also the majority of free or low-cost mammography, diagnostics and treatment for individuals referred from more than thirty health departments, community health centers, and free clinics in the area. Many people also travel to Fulton County from neighboring counties with less medical resources, so the resources within the county are strained.

Komen Atlanta funds three of the hospital systems located in Fulton County (Northside, Grady, and Piedmont) along with non-profit organizations who outreach to specific populations in need including African American women, Latinas, Asian Americans, new immigrant and/or transient populations, and LGBTQ individuals. Komen Atlanta also has a long time partnership with the Fulton County health department. Opportunities for the future include developing greater infrastructure within Fulton County to serve both the county residents and those who travel to the area while also maintaining smaller and highly competent outreach and screening programs that are best at educating hard to reach or highly underserved populations.

### Henry County

Henry County has few breast health providers. Piedmont Henry Hospital is the only organization providing at least one service in each part of the continuum of care. Some services, such as breast MRI, are not available in the county because Piedmont Henry refers to their main campus in Fulton County for those services. Henry County does have one health department location and a handful of community clinics providing free or low-cost clinical breast exams, but those organizations must refer patients to another facility for imaging or treatment.

Piedmont Henry is Komen Atlanta's only current partner in Henry County. Komen Atlanta should work to develop additional partnerships in the area to increase access to screening and other resources. As a semi-rural county with few medical facilities, Henry County would also benefit from mobile mammography services. Komen Atlanta will continue to work to make mobile mammography more accessible in target areas.

## **Public Policy Analysis**

### **National Breast and Cervical Cancer Early Detection Program**

#### *Overview*

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) strives to provide low-income uninsured and underinsured women with access to cancer screenings for breast and cervical cancer. NBCCEDP was established in 1991 through the Breast and Cervical Cancer Mortality Prevention Act of 1991 and is implemented through the Centers for Disease Control and Prevention (CDC). Within Georgia, approximately 35,000 women were provided with mammography services through the NBCCEDP between 2008 and 2012 (CDC NBCCEDP 2014).

#### *State Policy*

In Georgia, the state's public health department runs the Georgia Breast and Cervical Cancer program (BCCP), funded by both federal and state revenues through the NBCCEDP, the Master Settlement Agreement, and state resources. Despite its funding sources, the state only receives enough funding to provide breast cancer services to 16,000 women (Cobb & Douglas 2014), covering less than 15 percent of the program's eligible population (CDC Georgia 2014).

To be eligible for the BCCP, women must be a resident of the state, between the ages of 40 and 64, low-income (less than 200 percent of the federal poverty level), and uninsured. Through the BCCP, eligible women will receive clinical breast examinations, mammograms, and diagnostic evaluation in case of abnormal results. Should results be conclusive of breast cancer, women will be referred to treatment options through Georgia's Women's Health Medicaid Program. In order to enroll in the program or find a BCCP provider, women can contact their local county public health department (Georgia Department of Public Health 2014).

#### *Treatment Options*

Once diagnosed with breast cancer, women are eligible for Georgia's Women's Health Medicaid program, provided that they meet the same low-income requirements of the BCCP program, are younger than 65 years old, and do not have insurance or coverage for cancer treatment. In comparison to other states, Georgia has a less restrictive treatment option – women eligible for Medicaid are not required to have been diagnosed through the BCCP program. If her provider receives NBCCEDP funding and the administered service was within the scope of the state's program, a diagnosed woman can enroll in Georgia's Medicaid program (ACS 2010). Consequently, Georgia's less restrictive treatment option allows for a greater number of low-income and uninsured women to receive proper medical attention for her diagnosis, as well as any other medical needs throughout the course of her disease.

The effects of the BCCP and subsequent Medicaid treatment have been significant within Georgia. Studies have shown that through the passage of the BCCPTA and extension of the Women's Health Medicaid program, women are more likely to enroll in Medicaid earlier

– the time between diagnosis and enrollment decreased by 7 to 8 months (Adams, Chien, Florence, & Raskind-Hood, 2009). In comparison to other traditional Medicaid eligible groups, women enrolled through the BCCPTA were more likely to receive treatment (Adams, Chien, Gabram-Mendola, 2012), demonstrating that the program has become a path for greater access to services within the state.

### *Komen Atlanta and the NBCCEDP*

In order to support the NBCCEDP program, which remains significantly underfunded through its current sources, Komen Atlanta provides grants to health programs and providers that administer NBCCEDP services through its competitive community grants program. Due to the support of Komen Atlanta, these providers are able to screen more women and refer them to appropriate medical treatment if diagnosed. Komen Atlanta will continue to monitor the state of NBCCEDP funding and the availability of providers in the service area, funding providers through the grants program when possible and appropriate. Komen Atlanta will also advocate for continued or expanded funding for the NBCCEDP in keeping with Komen advocacy priorities.

## **Georgia Comprehensive Cancer Control Program**

### *Overview*

In 1998, the CDC established the National Comprehensive Cancer Control Program in an effort to reduce cancer-related morbidity and mortality through the creation of coalitions, assessment of burden and priorities, and development of tailored plans within each state (CDC NCCCP, 2013). Consequently, the Georgia Comprehensive Cancer Control Program (GCCCCP) was created as part of the CDC's national initiative. The GCCCCP is run by the Georgia Department of Public Health and aligns its goals and efforts with those of the Healthy People 2020 National Objectives. The GCCCCP brings together various stakeholders from the Georgia Cancer Control Consortium to develop the Georgia Cancer plan, in which priority cancer conditions are highlighted and plans of action are determined to help reduce rates of morbidity and mortality (Georgia Department of Public Health, 2013).

### *GCCCCP Breast Cancer Objectives*

In the 2014-2019 Georgia Cancer Plan, the GCCCCP has outlined several priority areas to focus its attention, including breast cancer. The GCCCCP acknowledges that breast cancer remains a leading cause of death within the state, and that if certain efforts, including increased screening rates, are undertaken, prevalence and mortality rates can be greatly reduced.

The breast cancer specific objectives outlined in the plan seek to ensure that all women have access to high quality screening, genetic screening, counseling, and preventative services. In order to meet their objectives, the GCCCCP strives to sustain current community-based screening programs that focus on racial and ethnic minority groups, with the goal of reducing disparities in screening rates by 10 percent by 2019. Additionally, the GCCCCP aims to promote genetic screening in an effort to increase the proportion of high-risk individuals receiving genetic risk assessment and appropriate screening by 25 percent. Furthermore, the GCCCCP seeks Medicaid and state insurance reimbursement for genetic

testing and counseling, as well as preventative procedures such as mastectomies in high-risk individuals. Additional preventative measures, such as educational campaigns focused on screening, the promotion of breastfeeding (which is linked to reducing the risk of breast cancer), as well as reduction in obesity, are also initiatives supported by the GCCCP (Georgia Cancer Control Consortium, 2013).

### *Komen Atlanta and the GCCCP*

Komen Atlanta works with Georgia CORE and other members of the GCCCP to increase screening in medically underserved communities. Komen Atlanta has limited coordination in advocacy efforts with the GCCCP at the present time, but Komen Atlanta will work over the next four years to partner with the GCCCP to promote legislation and policies that are mutually beneficial.

## **The Affordable Care Act**

### *Overview*

In 2009, the Affordable Care Act (ACA) was signed to improve access to healthcare and transform the American healthcare system. The provisions of the ACA are particularly beneficial to the prevention and treatment of breast cancer. Through the individual mandate and expansion of Medicaid, the law ensures that more people will receive insurance, consequently improving their access to healthcare and treatment. Additionally, women with already diagnosed breast cancer cannot be prevented from receiving insurance due to pre-existing conditions, or dropped from their existing plans due to their health state (ACS, 2013). Prior to the implementation of the ACA, many private insurance plans enforced gender rating, in which women were required to pay higher premiums for the same coverage as men – however, with the ACA, private plans are no longer allowed to charge women more than men (National Women’s Law Center, 2013).

The ACA also requires health plans, both private and public, to cover the cost of recommended preventative services. Mammograms will be provided at no cost to the patient, beginning at age 40 (based on the 2002 U.S. Preventative Services Task Force guidelines) for all insured women, in addition to BRCA1 and BRCA2 testing and counseling for high-risk women.

### *Medicaid Expansion in Georgia*

When initially signed, the ACA stipulated that states must expand their Medicaid eligibility to include individuals up to 138 percent of the federal poverty line. To cover the costs of the expansion, the federal government would fund 100 percent of the expenditures for the newly eligible population until 2016 and gradually decrease its contribution to 90 percent by 2020. However, in the case of *National Federation of Individual Business v. Sebelius*, the Supreme Court found the Medicaid mandate unconstitutional and instead left the decision to expand Medicaid to each state’s discretion.

As a result of the Supreme Court’s decision, Georgia decided not to expand its Medicaid eligibility. Consequently, Medicaid is limited to parents below 38 percent of the federal poverty line, resulting in a gap in which childless adults and those between 38 and 138



percent are not eligible for Medicaid. Prior to the implementation of the ACA, an estimated 2,107,000 individuals were uninsured within Georgia (Holahan, Buettgens, Carroll, & Dorn, 2012). As of April 2014, this number was reduced to 1,849,000 (Henry Kaiser Foundation, 2014). Conversely, if Georgia decided to expand Medicaid, the percentage of uninsured would have been reduced by 51.3 percent (Holahan, Buettgens, Carroll, & Dorn, 2012).

#### *Effects of the ACA on the NBCCEDP*

Due to Georgia's decision not to expand Medicaid, more than 266,000 women will not have access to health insurance (ACS, 2013), indicating that the need for screenings through the NBCCEDP and coverage through Women's Health Medicaid remains significant within the state. However, due to the individual mandate and the essential benefits covered through the ACA, women who are able to purchase individual plans through the market with the aid of tax credits and subsidies, or women who were previously underinsured, will now have access to no-cost screenings and will not be prevented from enrolling in insurance due to their gender or pre-existing conditions. With this decrease in the population in need of NBCCEDP services, more women can be screened through the program.

Conversely, the provisions of the ACA do not cover diagnostic tests after the initial screening. Follow-up or secondary testing such as biopsies and other imaging may be subject to deductibles or copayments; consequently, low-income women may not be able to afford the additional costs and may further delay treatment. NBCCEDP funding covers additional diagnostic tests and can provide coverage to women in need. Nevertheless, the program remains underfunded and requires continued and increased funding to support its services and provide screenings and testing for all women in need.

#### *Effects of the ACA on Providers*

By improving access to health insurance, as well as guaranteeing coverage of essential benefits, the ACA allows for the reduction of uncompensated care that many providers had to face, as well as increases the number of patients that will be seen by providers. Furthermore, insurance companies will be held more accountable for their payments to providers and cannot deny or rescind patient coverage. Stronger integration of care across providers will also facilitate better communication between different providers in the care of their patient and decrease administrative burden that often hinders effective care.

#### *Effects of the ACA on Komen Atlanta*

As a result of the ACA, the number of uninsured women who require access to breast cancer screenings and treatment will decrease slightly in Komen Atlanta's service area. However, Georgia's decision not to expand Medicaid ensures that a significant portion of the population continues to require assistance through NBCCEDP and community health centers aided by Komen Atlanta. In particular, undocumented immigrants, who are excluded from federally funded insurance as well as subsidies in the insurance marketplace, remain a noteworthy population that requires assistance in accessing breast cancer screenings and treatment.

### **Komen Atlanta's Public Policy Activities**

#### *Oral Chemotherapy Advocacy*

Komen Atlanta was a supporter of Georgia's House Bill 943, the Cancer Treatment Fairness Act (16). HB 943 addresses the issue of oral chemotherapy parity by amending state law to allow for a reduction in the patient's cost-sharing requirements for oral therapies. Oral anticancer medications have become increasingly popular, as they eliminate barriers to treatment accessibility such as transportation and time costs associated with intravenous chemotherapy. Prior to the passage of HB 943, intravenous and oral anticancer medications were considered as separate benefits – intravenous chemotherapies were covered under health plans, while oral chemotherapies under prescription plans. Consequently, oral drugs often cost patients significantly higher payments compared to intravenous drugs, resulting in patients' failure to fill prescriptions due to high costs.

To eliminate the discrepancy between intravenous and oral drugs, HB 943 requires private health plans to cover oral cancer treatments, shifting coverage away from prescription plans and eliminating its cost-barriers. Furthermore, a limit of \$200 per month is placed on patients' copayments, coinsurance, or deductibles. Although Komen Atlanta supports the legislation, the success of the bill is not complete; Komen Atlanta was advocating for a \$50 per month cap on patients' out-of-pocket costs. While \$200 is an improvement to the previous cost structure, studies have shown that 10 percent of patients tend to forego treatment if out-of-pocket costs are greater than \$100. Therefore, Komen Atlanta continues to advocate for the further reduction of patients' costs.

#### *Metastatic Breast Cancer Awareness Forum*

In October 2013, in recognition of Breast Cancer Awareness month, Komen Atlanta sponsored the Breast Cancer Awareness Forum at the Georgia State Capitol, in conjunction with the Georgia Women's Legislative Caucus and the Center for Black Women's Wellness. The event brought together legislatures, advocates, and survivors for a policy briefing that highlighted the need for prevention in Georgia, as well as increase awareness of the issue.

### **Georgia State Laws**

#### *Medicaid Limitations*

In addition to addressing the issue of oral chemotherapy parity, HB 943 includes a clause that prevents any state agency from using funds in activities deemed to advocate or influence citizens in supporting Medicaid expansion. Through this restriction, the bill essentially limits the advocacy surrounding expansion and allowing citizens to become informed of its merits.

Similarly, HB 990 constrains the power of future governors and leaders from expanding Medicaid without prior legislative approval (HB 990, 2014). As the ACA left the decision of Medicaid expansion to the discretion of state governors, HB 990 represents a severe limitation on the power of future governors. Given Georgia's history, expansion of Medicaid in the near future seems unlikely through the passage of this bill.

As previously discussed, Georgia's expansion of Medicaid would allow for thousands of women to access regular screenings and ensure healthier outcomes. Georgia's decision not to expand has resulted in a gap between women who have insurance and those who cannot afford it, further constraining the limited resources provided by the NBCCEDP.

## Conclusion

### *Future Policy Improvements*

1. *Expand Medicaid:* Despite the restrictions placed on Medicaid expansion through house bills 943 and 990, Georgia would greatly benefit in expanding Medicaid to low-income, childless adults. Increased accessibility to insurance and healthcare would allow for thousands of women to receive recommended screenings, address risk factors, and receive necessary treatment for breast cancer. Additionally, by providing coverage to this population of women, funding for NBCCEDP services can be redirected to reach additional populations not covered by insurance, especially immigrant women and women with language and literacy barriers that limit their utilization of screenings and services.
2. *Further reduce the cost of oral anticancer medication:* Although the passage of the Cancer Fairness Treatment Act greatly improves upon the parity issue surrounding oral therapies, the cap on out-of-pocket costs to the patient remains too high for many low-income patients. Consequently, treatment compliance will be negatively affected within this population, hindering successful treatment and recovery. Komen Atlanta continues to advocate for a reduction in out-of-pocket costs from \$200 to \$50 per month.
3. *Expansion of Women's Health Medicaid:* Currently, Georgia employs treatment option 2, in which women who are screened by providers who receive NBCCEDP funding are eligible for Women's Health Medicaid. However, when the BCCPTA was initially enacted within the state, Georgia opted for treatment option 3. During this period, all eligible uninsured and underinsured women, regardless of provider, were able to enroll in Women's Health Medicaid in the event of positive diagnosis. If Georgia reverts back to option 3, the gap in treatment and insurance coverage for diagnosed breast cancer patients will be greatly minimized.

### *Additional Goals*

Despite the many recent changes (both improvements and limitations) to preventative measures and access to care, gaps still exist among women in Komen Atlanta's service area. Undocumented immigrants are exempt from receiving federal or state financed health coverage, and represent a significant population that lacks proper access to screening and treatment services. Additionally, women with language and literacy barriers are often unaware of their screening options and providers. Consequently, Komen Atlanta seeks to improve accessibility of services among this population with outreach efforts and funding providers within immigrant populations to facilitate communication and better use of offered services. Furthermore, additional funding should be provided to support BCCP programs, as the program covers only a minimal portion of the eligible population, and Georgia's decision not to expand Medicaid retains a substantial population in need of BCCP services.