

# **Overcoming Stigma with a Collaborative, Comprehensive Community Approach: Fostering Public and Private Engagement For Preventing HIV/AIDS and Promoting Lifelong Wellness**

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## **Introduction**

The need for AIDS Service Organizations (ASOs) to be relevant to their communities and ultimately foster effective engagement with primary health care and community-based organizations is the single greatest opportunity facing ASO leaders today. ASOs worldwide can create places where an efficient, one-stop continuum of healthcare and lifelong support services help those impacted by HIV/AIDS.

During a time of healthcare upheaval and change across the globe, community-based ASOs are challenged to keep those impacted with HIV/AIDS in the healthcare system. The uphill battle for one person to live well and strong with this complex, chronic disease, while protecting others from becoming infected, requires a steady supply of medical, emotional, and social support.

Since ASOs began in the U.S. about 30 years ago, these organizations have evolved from being volunteer-driven to now requiring leaders and staff who demonstrate top administrative skills as well as resiliency, flexibility, and entrepreneurship. As AIDS has matured into a chronic disease, community engagement is more essential than ever before to understand how to serve diverse needs of communities. In the U.S., AIDS has evolved from being stereotyped as a “gay man’s disease” to a broader understanding that the disease also impacts women, youth and as well as those infants born with the disease. Furthermore, as government funding for support services (e.g. behavioral health, psychosocial support, etc.) has decreased, the need to help people take responsibility for their own lifelong wellness – staying adherent to medications, for example – has increased as an AIDS prevention strategy.

By using Southwest Center for HIV/AIDS as a case study for a collaborative, community-based approach, this paper focuses on how ASO leaders can develop an innovative, one-stop model of integrative healthcare and support services.

Southwest Center for HIV/AIDS in Phoenix, Arizona, USA – the sixth-largest metropolitan area in the United States – has reached out to create widespread community engagement around HIV prevention, education and chronic disease management. For more than 21 years, Southwest Center has provided a collaborative model in an innovative public-private healthcare model to address HIV/AIDS as a long-term, chronic disease. Southwest Center serves 70 percent of Arizona’s nearly 14,000 infected residents in addition to the more than 30,000 at-risk individuals in the metropolitan area.

The Phoenix metropolitan area, often referred to as The Valley of the Sun, is a metropolitan area with a population of approximately 4.2 million centered within and around the city of Phoenix. The metropolitan area includes 33 incorporated cities of various sizes, as well as 28 smaller unincorporated towns within Maricopa and Pinal counties.

Southwest Center's vision is to lead the fight to end the HIV/AIDS epidemic. Our mission is to prevent infection, to improve quality of life for those impacted by the disease by increasing access to care and optimizing health outcomes for people living with HIV, and to contribute to worldwide research through clinical trials and non-clinical studies. Our three distinct areas of focus include prevention initiatives, chronic disease wellness and research. Our clinical trial research has helped bring 29 of the available 32 HIV/AIDS medications to market.

Approximately 50 percent of Southwest Center's clients are White or non-Hispanic; 28 percent are Hispanic, 6 percent are Black, and 16 percent are bi-racial or classified as Native American, Asian-Pacific Islander and other. Approximately 84 percent of Southwest Center's male clients are men over the age of 25. Thirteen percent of Southwest Center's clients are women over the age of 25, and 3 percent are youth.

The move toward an integrated "medical home" model of primary and HIV support services is a movement gaining momentum in the United States. This integrated healthcare model has been in place at Southwest Center for more than 17 years as the history of the AIDS epidemic has evolved in the U.S.

### **From grassroots to National Strategy: History of AIDS and community engagement**

In the United States, the human rights and gay rights movements of the 1960s and 1970s served to prepare AIDS activists to vocalize the need for government support when AIDS was first discovered in 1981. Poindexter (2008) succinctly noted that ASOs began as grassroots, alternative, community-based advocacy entities designed to address institutional neglect. Early ASOs were lifesavers. Not only did they produce social support services and public health information to communities at risk, lessening economic, psychological, and social impacts of the pandemic, they supplemented and expanded what formal health and social service systems provided (Fleishman, Piette, & Mor, 1990).

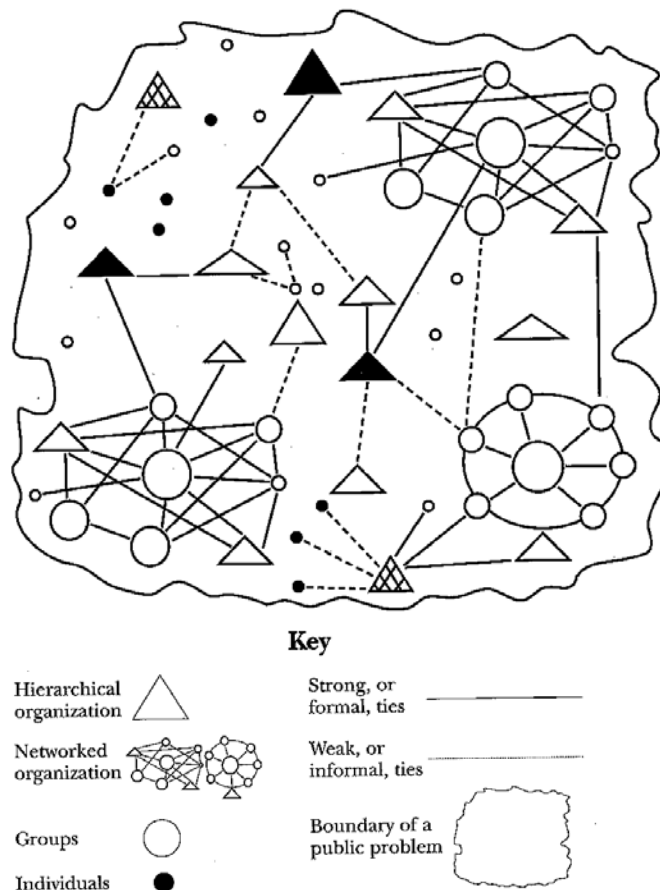
Many grassroots initiatives sprung up in local communities to address special emotional and physical needs of those impacted by the disease. Figure 1 depicts the early days of AIDS, where, in a shared-power situation where many organizations exist and no one entity is in charge, part of the difficulty is gaining rough agreement on what the problems are (Crosby & Bryson, 2005). AIDS-related organizations came in various sizes and structures, from large hierarchies providing primary healthcare, to diffuse networks. AIDS support in the early days included volunteers providing hospital visitation, home-care and meal support. As small, scattered groups provided volunteer services to help ease the isolation and stigma of the disease –more coordinated resources were needed to try to bring consensus on public policy, goals, programs and actions needed to solve the vast HIV/AIDS problem.

In 1988, seven years after the effects of HIV were first noticed, there were more than 400 ASOs in the United States alone. They were grassroots in nature and tended to be founded and staffed by gay men and/or HIV-infected persons, with allies and volunteers from other groups, as an immediate care giving and fundraising response to the emergency (Andriote & Kawata, 1988). The first ASOs created services and nested them in an innovative model that was cost-effective,

flexible, individualized, accessible, culturally competent, and delivered by committed volunteers (Cain, 1997; Chambre, 1991; Poindexter, 2002; Wilson, 1995).

Southwest Center began in 1988 as “Phoenix Body Positive” in the living room of its founder, Kirk Baxter. Kirk was a college student at Arizona State University and was impacted by the disease. An initial grant was secured, helping to launch the start-up of the first HIV clinical trial in Arizona. During the 1990s and decade following, the agency grew exponentially under executive directors Brian Spicker and Brian Helander as government funded expanded across the U.S. During 1991, the first year of the Ryan White HIV/AIDS Program, the federal budget appropriation was \$220.6 million. By 2010, it had grown to \$2.29 billion. (HRSA, 2011).

Southwest Center grew from the first \$25,000 grant to \$3.6 million in prevention and support services by 2005, thanks to federal grants and large-scale community fundraising initiatives that grew to large-scale – galas, concerts, and a dining-out restaurant event. As community-based funding grew, Southwest Center was able to start up a licensed mental health clinic and add nutritional services and more than 15 programs for men, women, and at-risk youth.



**Figure 1: Numerous AIDS organizations trying to address the early AIDS epidemic in the United States, where no one entity is in charge (Crosby & Bryson, 2005).**

Although ASOs emerged out of grassroots activism, the HIV field has followed the pattern of many social change movements that become professionalized and more bureaucratized. Small, grassroots organizations have folded, and many surviving ASOs have merged and are struggling to survive today. As ASOs grow larger, more bureaucratic, and slower to respond to demands or environmental changes, they more closely resemble the organizations they were formed in opposition to (Cain, 1997).

ASOs now face management challenges common in all alternative agencies in later stages and challenges unique to the HIV field. Stigma, changing practice contexts, volunteerism, partnership, cultural competence, financial health, professionalism, service integration, job stress, and organizational cohesion are presented as typical challenges and contexts, paired with strategies to address them. Managers in the HIV field must balance many competing forces as the pandemic increases while funding and attention decrease.

As is the case with alternative agencies moving toward the mainstream, certain funding sources may force ASOs into a more conservative or rigid framework, causing them to compromise their flexible approach and advocacy stance (Perlmutter, 1988). Accepting federal funding has dictated the ways in which HIV programs are delivered, with rigorous reporting standards that require sophisticated grant management and reporting, including financial reporting for every dollar spent. This has presented a dramatic shift in skills and internal culture needed. Many small ASOs without capacity to manage contract requirements no longer are in business. Some have merged with larger organizations to stay afloat in an era of limited government and private resources.

Due to the global movement toward urbanization, the need for integrated HIV medical care and support services has grown. Those living in rural areas are moving to large metropolitan areas or “megapolitan” cities that create jobs and economic opportunities. In the U.S., ten primary megapolitans regions are emerging and are projected to account for 64 percent of total population growth and 62 percent of all new jobs created in the contiguous 48 states from 2000 to 2030, adding 62 million residents during this time frame (Crow, 2011). As people move from rural to urban areas, the large megapolitans must address HIV/AIDS as regions of high risk. In the U.S., the first national strategy to fight the HIV/AIDS epidemic has become a profound catalyst for targeting HIV testing and connection to healthcare prevention strategy for at-risk populations in high-risk megapolitan areas.

### **Impact of the National AIDS Strategy of 2010 on community engagement initiatives**

In the U.S., a pivotal driver of change is the National AIDS Strategy of 2010. The strategy provides a roadmap for public and private stakeholders to better address the ongoing HIV epidemic. The three primary goals are to reduce the number of people who become infected with HIV, increase access to care and thereby optimize health outcomes for people living with HIV, and reduce HIV-related health disparities.

**The United States will become a place  
where new HIV infections are rare and when they do occur,  
every person regardless of age, gender, race/ethnicity,  
sexual orientation, gender identity or socio-economic circumstance,  
will have unfettered access to high quality,  
life-extending care, free from stigma and discrimination.**

**U.S. National HIV/AIDS Strategy Vision  
[www.AIDS.gov](http://www.AIDS.gov)**

As the AIDS epidemic today focuses on getting people into healthcare, U.S. government funding has shifted away from support services towards a primary health care focus and core services delivered by the primary care physician coordinating with other providers of services that have proven to be most effective for HIV prevention and on-going care of those infected. For ASOs, the emphasis is on providing a comprehensive “medical home” model of care. This means linking those diagnosed as HIV-positive directly to healthcare and lifelong support services.

In order to help those who are HIV-positive secure medical care and medications, ASOs must either be integrated with primary care services, or seeking to co-locate with primary care in order to provide a seamless array of support services. Federal funding is focused on the largest metropolitan cities with the largest population of communities at highest risk and at greatest disparity due to cultural stigma associated with HIV/AIDS. In Arizona and across the U.S., this includes Black/African American and Latino communities.

For Southwest Center, the medical home model of service integration will continue to place the patient in the center surrounded by three support systems with sharper focus than ever before. Medical home model means three things to Southwest Center. First, integrated space that provides a welcoming, one-stop community health location open and accepting of all ages, genders, and ethnic cultures. Second, a schedule of programs and services that integrates primary healthcare appointments with surrounding support services. Services include behavioral health services like counseling and mental health support groups, medical nutrition, education, naturopathic remedies. We also provide a retail vitamin shop managed by Southwest Center, and an HIV/AIDS specialty pharmacy on site operated by a commercial pharmacy that has built a reputation for supporting chronic diseases. Third, critical to this plan is an integrated electronic medical record system where patient data helps the providers offer one-stop, seamless service to more knowledgeably serve patients/clients.

For some ASOs, efforts to move toward the medical home model is a huge paradigm shift and requires an abrupt departure from “business as usual.” Some ASO leaders are contemplating how to become a Federally Qualified Health Clinic (FQHC) or “look-alike FQHC” in order to gain government subsidies by providing primary care. Others are wondering how to become co-located with an FQHC. In the words of one ASO executive, there will be “no more AIDS Inc.” where vast array of support services and prevention programs stand alone as boutique support-service programs without some connection to primary care and rigorous impact measurement if the programs are to remain government-funded.

### **The challenge of providing support services for HIV/AIDS as a chronic disease**

People can live for decades with HIV/AIDS with the help of medications, but only if they stay physically and emotionally healthy and strong. Services such as mental health and nutrition counseling, vitamin regimens to boost the immune system, acupuncture to relieve pain from the side effects of medication, and medical massage to promote circulation have proven to help people live as strong and long as possible with HIV/AIDS.

Because federal funding is being eliminated for many valuable support services Southwest Center for many years has developed a private fundraising program to support the core services still funded by the U.S. government. Private funding has helped us reach out beyond the walls of our agency, as well as bring the public into our community health and education center for prevention services. We have established community outreach programs for communicating an age- and school-appropriate prevention message in public schools across the Phoenix area.

HIV/AIDS is now seen as a chronic disease – while sharing many commonalities, there are many unique nuances that go well beyond medical care, requiring community engagement and support, not forgetting prevention and research, while connecting wellness support to primary care.

HIV/AIDS is widely recognized as a chronic illness. Similar to other chronic diseases, HIV requires lifetime changes in physical health, psychological functioning, social relations, and adoption of disease-specific regimens (Swendeman, 2009). The shift from acute to chronic illness requires a self-management model in which patients assume an active and informed role in healthcare decision making to change behaviors and social relations to optimize health and proactively address predictable challenges of chronic diseases generally and HIV specifically.

According to Swendeman (2009), an integrated framework of common elements in chronic disease self-management focuses on three broad categories: physical health; psychological functioning; and social relationships. Common elements for physical health include: a framework for understanding illness and wellness; health promoting behaviors; treatment adherence; self-monitoring of physical status; accessing appropriate treatment and services; and preventing transmission. Elements related to psychological functioning include: self-efficacy and empowerment; cognitive skills; reducing negative emotional states; and managing identity shifts. Social relationship elements include: collaborative relationships with healthcare providers; social support; disclosure and stigma management; and positive social and family relationships.

HIV meets several chronic disease criteria: uncertain course, a prescribed treatment regimen, requirement for self-care, some degree of stigma, changes in roles and relationships, identity changes, and psychological distress (Siegel & Lekas, 2002). The goal of chronic illnesses healthcare is to control or manage symptoms, improve independence and quality of life, and prevent disability rather than cure the disease (Creer, Holroyd, Glasgow, & Smith, 2004). The majority of chronic disease illness management takes place outside of formal healthcare with patients engaged in day-to-day “illness work” (Gately, Rogers, & Sanders, 2007; Corbin & Strauss, 1995).

With chronic illness being prolonged or lifetime in nature, in contrast to acute illness, the patient is the principal caregiver. Patients are responsible for: using medication properly, changing behavior to improve symptoms or slow disease progression, interpreting and reporting symptoms correctly, adjusting to new social and economic circumstances, coping with emotional consequences, participating in treatment decisions, and preventing transmission of contagious diseases (Holman & Lorig, 1997). Thus, the shift from acute to chronic care brings emphasis to self-management of disease, where patients assume an active and informed role in managing physical, psychological, and social aspects of health.

Swendeman notes that there is a global need to scale up chronic disease self-management services, including for HIV, but there are significant challenges related to healthcare system and provider capacities, and stigma is a significant barrier to HIV-identified service utilization. Recognizing that self-management of HIV has more likenesses than differences with all chronic diseases suggests that the design and delivery of HIV support services can be incorporated into combined or integrated prevention and wellness services.

For many years, Southwest Center has provided a cost-effective, integrated primary care and support services for HIV/AIDS patients by its strategic co-location with Arizona’s largest public health clinic, McDowell Healthcare Center. In 2012, Southwest Center will move into a community-partnered, new community health center. This integrative model is expected to

expand its reach to reduce stigma among communities who customarily do not discuss HIV/AIDS, as well as become an important wellness resource for other chronic diseases.

**Overcoming stigma, aligning with the National AIDS Strategy, and partnering with primary care: Southwest Center's Center for Health Education and Community Wellness**

In 2006, Southwest Center for HIV/AIDS was designated as the fiscal agent by the City of Phoenix through the 2006 bond election, whereby Southwest Center received citizen voter approval for \$3.6 million in public funding to establish a community health center. This one-stop



health and educational resource will serve a population of more than four million people living in the greater Phoenix area, offering a comprehensive, cost-effective model of health service delivery.

The Center for Health Education and Community Wellness will meet growing public needs for providing HIV/AIDS education, prevention, wellness and research services for as many as 18,000 Arizonans who are impacted by the disease and more than 30,000 who are considered at-risk.

After an extensive search of properties, a 50,000 square-foot facility – once the home of the local Gannett/NBC television news station, was selected. In October of 2010, the Phoenix City Council approved the City of Phoenix to pursue the purchase of this facility. The building is steps away from light rail and public bus transportation in the center of the downtown Phoenix urban core. Joining Southwest Center will be the McDowell Healthcare Center, the largest public HIV/AIDS specialty clinic in Arizona, managed by Maricopa Integrated Health System.

The focus of the Center will be to end the AIDS epidemic through research, prevention via education, and prevention with and through those who are HIV-positive by connecting those infected directly to healthcare and chronic disease management. A distinguishing feature of the Center for Health Education and Community Wellness will be the full continuum of HIV/AIDS primary care, research, prevention, and chronic disease wellness support. The one-stop location near public transit provides convenience for those who need an array of medical and support services to address lifelong, chronic healthcare needs. Other public benefits include the opportunity for shared meeting and conference spaces leading to new revenue streams to support operations.

The Center is expected to be a model of excellence for other types of long-term, chronic diseases impacting the lifespan of men, women and youth in diverse communities. Not only will the facility serve the most underserved populations in the Phoenix area, the upscale new facility will draw residents from a variety of socioeconomic classes who otherwise may not visit the current clinic. At the city's core and adjacent to the largest greenbelt park in Phoenix and Arizona's largest public library, Southwest Center will create an inclusive, community center that is open

and accessible to the public as well as positioned in the medical and biotech corridors, making the facility highly collaborative as a national health and wellness center.



The facility will provide a high-profile community health and education center in downtown Phoenix – the first of its kind in Phoenix providing integrated HIV/AIDS primary care and support services combined with shared classrooms for education programs for men, women, and youth of all ages and ethnic backgrounds, including the lesbian, gay, bisexual and transgender (LGBT) community.

Services will include but are not limited to:

- Primary Care
- HIV/AIDS Clinical Trials
- Collaboration with university research initiatives and medical student rotations
- Dental Services
- Educational workshops for youth, women and men
- Mental health (psychosocial) support groups for impacted youth, women and men
- Individual, family and group mental health counseling
- Nutrition counseling
- Vitamin shop for supporting wellness and chronic disease management
- On-site pharmacy, helping people stay medication adherent
- HIV/AIDS prevention/education programs
- Child Watch parent service
- Workforce development
- Promoting healthy lifestyle choices to members of Arizona’s growing LGBT community, an underserved population
- Education addressing violence prevention, self esteem, and other topics relevant to high-risk populations
- Volunteer training and deployment
- Complementary Alternative Medicine to assist HIV/AIDS clients with wellness support and chronic pain management



The one-stop wellness programs provided in at the Southwest Center conservatively is estimated to save Arizona taxpayers \$16 million annually in avoided costs in public subsidization of costs associated with hospital stays for those impacted with HIV/AIDS, based on the average hospital stay for people living with HIV/AIDS in the U.S. (Research Triangle Park, 2008).



Our community health and education center facility will enable the Southwest Center to expand its collaborative partnerships with community-based, minority service organizations in providing prevention, behavioral health support groups, wellness support services, and clinical trials research. Renovation within the space as well as collaborative partnerships will establish a culturally (and linguistically) appropriate environment to serve the diverse communities and needs of the Southwest. Critical information and resource services will include a multi-use lecture hall, community rooms for meetings, training rooms, a resource library and Internet center for online information resources.

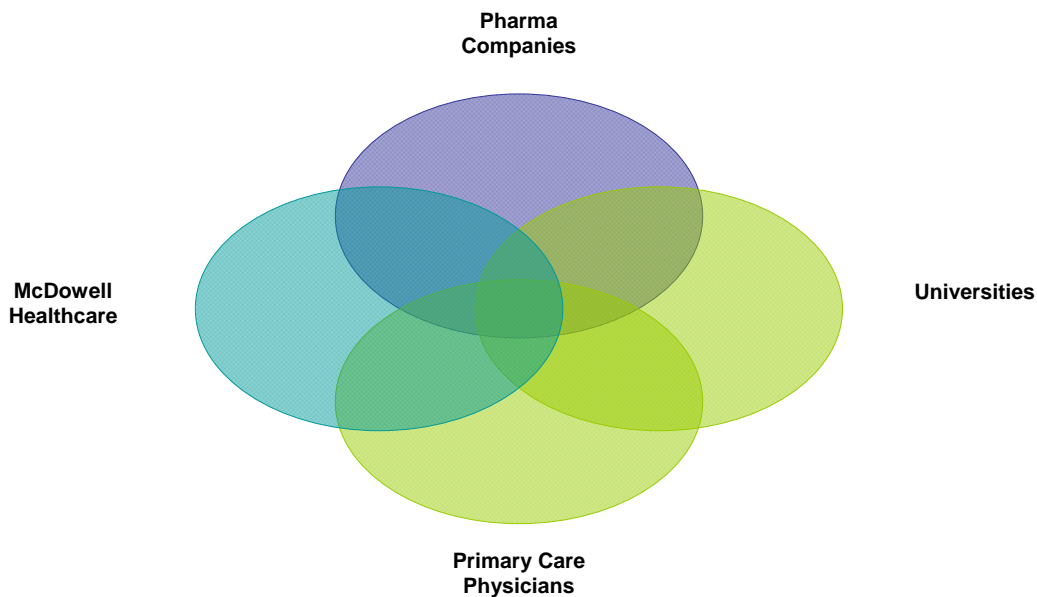
## **At Southwest Center: Research, Prevention, and Chronic Disease Wellness**

### **Research and Community Engagement**

Southwest Center in the early 1990s became, and remains today, the largest privately supported clinical trial operation in the U.S. Desert Southwest, and remains as such today. Our vision states that we “bring hope for an AIDS-free generation through clinical research that advances the prevention of new infection, and through research that supports an ultimate cure for HIV/AIDS.”

Southwest Center’s founding principal investigator, Dr. Andy Myers, developed collaborative working relationships with nearly two dozen local primary care doctors who provided a significant amount of patient care treating HIV/AIDS. The remaining 50 percent of our clinical trial participants are referred by the McDowell Healthcare Center co-located in our current building. Southwest Center obtains studies through its stellar reputation with pharmaceutical companies, HIV physicians, select hospitals, and through formal university partnerships.

To establish a collaborative relationship, it was important for us to emphasize that Southwest Center must work through the patient’s primary care physician. We did not want to become primary care providers. Our goal was to participate in clinical trial research that would provide vanguard medications for those who otherwise would not have access to the drugs. Figure 2 shows how Southwest Center partners with our research community.



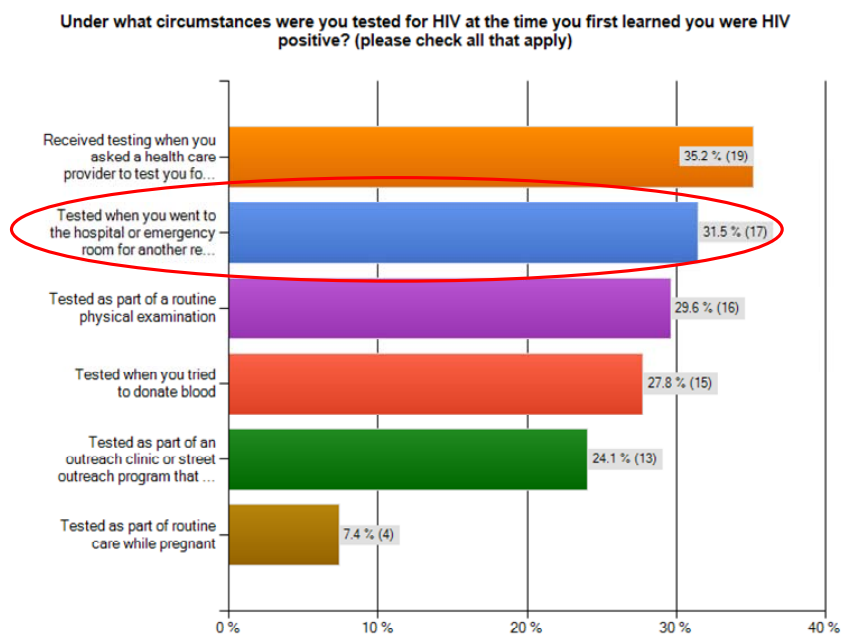
**Figure 2: Southwest Center clinical research referral partnerships.**

By 2008, it was clear that Southwest Center could not maintain certain types of trials as a nonprofit ASO. We developed a community-based research advisory committee and reorganized the clinical trials to become more efficient with less staff, better negotiated new trials, and focused on a greater variety of trials, including device testing such as HIV home test kits, HIV drug side effects (such as diarrhea and neuropathy), and co-morbidity research (HIV and diabetes, heart disease, etc.) This community-based advisory panel opened new doors of collaboration with Arizona’s biomedical and research communities.

In addition to refine existing medication regimens, Southwest Center will support research for the *cure* of HIV/AIDS, including the support of PreExposure Prophylaxis (PrEP). PrEP is part of comprehensive HIV prevention services in which HIV-negative people who are at high risk take antiretroviral medication daily to try to lower the chances of becoming infected with HIV if they are exposed to it. To date, PrEP has been shown to be effective in men who have sex with men (MSM) and heterosexual men and women. A Centers of Disease Control (CDC) study is underway to evaluate whether it is safe and effective in reducing HIV infection among injection drug users; results are not yet available.

Moreover, Southwest Center is using nonclinical research to determine how to partner with other agencies focusing on chronic diseases for future research opportunities. For example, a federally funded Ryan White study of the Phoenix area shows that 31.5 percent of individuals who tested HIV-positive were informed while visiting a hospital emergency room (Figure 3).

## Using research to understand the needs, gaps, opportunities among community constituents



**Figure 3: Community-based research showing opportunities for ASOs to partner with hospitals in the Phoenix area, linking people to healthcare and HIV/AIDS support services.**

This information has led Southwest Center to begin assessing how we might partner with local hospitals in high-risk neighborhoods for helping to connect those diagnosed in hospitals with ongoing healthcare and support services.

The CDC projects that half of the HIV-positive population in the U.S. will be 50 years or older by 2015. It is widely recognized that as chronic conditions increase, quality of life for those impacted by HIV/AIDS decreases. A recent PRIME PROJECT study (Balderson, Mahoney, Catz, 2011) examining HIV-positive persons ages 50 and older showed that the most common chronic conditions co-occurring with HIV/AIDS are high blood pressure (46 percent), chronic pain (45 percent), hepatitis (39 percent), arthritis (35 percent), chronic back pain (33 percent), asthma (32 percent), diabetes (21 percent), urinary/bladder (19 percent), chronic headaches (17 percent), loss of vision (15 percent), heart disease (13 percent), stomach ulcers (13 percent), neurological conditions (11 percent), cancer (10 percent), and loss of hearing (10 percent), osteoporosis (7 percent).

The PRIME Project's research (n = 452) found that 92 percent had two or more chronic diseases in addition to HIV (Balderson, Mahoney, Catz, 2011). This research is informing Southwest Center's community partnership initiatives, helping us determine disease-specific nonprofit and health-related organizations with which to partner.

## **Prevention and Community Engagement**

As mentioned earlier, similar to most ASOs in the United States, Southwest Center's early prevention initiatives were volunteer-driven, grassroots efforts to distribute condoms on the streets of high-risk neighborhoods and at bars. Through the late 1990s, condom distribution at gay bars and grassroots prevention programs primarily aimed at gay men were funded by the growing Ryan White federal program to support HIV/AIDS prevention initiatives.

During the past five years, prevention focuses on the opportunity to identify more HIV-infected individuals and to bring them into the health care system as a critical step in further stemming the tide of the HIV/AIDS epidemic (Cheever, Lubinski, Horber, & Steinberg (2007). By 2008, Southwest Center still boasted "AIDS Inc.," proudly promoting at least 15 prevention programs to support men, women, and youth. But many programs once funded by multiyear government grants were not able to prove real and lasting impact or became stale in effectiveness.

For example, Southwest Center conducted an eight-year prevention program for at-risk men. The two-day workshop presented a number of recruitment challenges associated with a large and spread-out metropolitan city. Issues included lack of transportation, people attending for a free meal, and losing participants on the second day. Large investments for prevention initiatives are likely to be shifted toward primary care rather than workshops that attract smaller volumes of at-risk attendees where prevention outcomes are difficult to measure to prove efficacy of the intervention.

Regarding web outreach, Southwest Center has struggled with understanding how to best maximize the Internet to actively seek out and intervene with at-risk online communities. Research suggests that it is becoming common for high-risk individuals to meet sexual partners online and those who do reported higher rates of substance abuse, more sexual partners, and unprotected sex (Bull, McFarlane & Reitsema, 2001). While some ASOs have used online chat rooms, chat room banner ads, and online AIDS hotlines, Southwest Center notes that many of our economically disadvantaged clients cannot afford a computer. While we promote our programs and opportunities for community engagement on our web site, we have more work to do in order to engage our community through online promotion of HIV testing, linkage to care, phone based texting and medication adherence strategies. Internet prevention seems to offer new and interactive opportunities for reaching diverse audiences over time.

### **Reaching underserved communities where significant stigma exists**

Southwest Center's prevention strategy emphasizes a Monday through Friday HIV testing and counseling clinic. Knowing one's HIV status is the first step in preventing the spread of the disease, as well as connecting newly diagnosed to healthcare, case management, and other essential community-based support services. Southwest Center is in the process of building up an EIS program that will include peer navigators and including treatment readiness support and treatment adherence education, partnering with specific community resources.

To more effectively reach high-risk Black and Hispanic men and women, Southwest Center hires a diverse work force. We provide workshops in community-based organizations outside of the agency, in our partners' venues. We work with the partnering groups to shape testing and counseling outreach as well as workshops and support groups. Groups include Chicanos Por La Causa, Via Del Sol, Native Health, and Ebony House. As Southwest Center goes into the community venues where we serve, we often find that underserved communities experience the

personalized, welcoming approach and are less afraid to visit programs offered on site at Southwest Center.

### **Helping the newly diagnosed**

A few years ago, we realized that our “go-to” programs were weak regarding the newly diagnosed. Today, we have a suite of services focusing on newly diagnosed, early intervention, and connection to healthcare.

In 2009, the Southwest Center introduced a rain-or-shine weekly orientation program directly connecting newly diagnosed individuals with healthcare and other resources. The majority of attendees were referred directly from our HIV testing program and the consistency of predictable orientation sessions provides a “stepping off” point for those who do not know what to do next after the shock of the HIV-positive diagnosis. During the first few months the programs were active, Southwest Center was able to connect more than 250 individuals to medical services, provide emotional and mental health services and support, and partner with case managers who could then provide support with the client’s ongoing management of the disease. In turn, the case managers would often refer newly diagnosed into our program.

Beyond the orientation, Southwest Center’s *Newly Diagnosed* support group was created to provide ongoing support for the first year after someone is newly diagnosed with HIV/AIDS. Groups are facilitated by licensed mental health counselors and discussion topics include coping with initial diagnosis, disclosure to others, healthy living, navigating healthcare, communicating to your doctors and planning for the future. Individuals who are newly diagnosed with HIV have an opportunity to connect with one another and receive professional support during six week support groups.

In addition to Southwest Center for HIV/AIDS has created a safe, confidential and highly successful HIV 101 program trademarked as *Pizza and the Basics*. The basic fundamentals of HIV/AIDS are presented by a collaborative group of four facilitators: An RN, an HIV specialty pharmacist, a prevention specialist, and a Southwest Center client – usually a long-term HIV/AIDS survivor who is trained as a peer leader. It is especially important for those with a new HIV diagnosis to become empowered through education and encouragement, to understand their need for responsible and safer sex practices and to connect with a specialist for comprehensive HIV care. Attendees learn all aspects of the infection, including transmission, testing, the effect of the virus on the immune system, the complexities of treatment, and the importance of adherence.

Our workshop now is in Spanish, *Pizza y Algo Mas*. The Spanish program reaches out to a growing number of those living with HIV/AIDS in our community who are Hispanic and monolingual.

Southwest Center funds a weekly Men’s Health Day every Wednesday, where HIV-positive men attend a lunch-and-learn program. Lunch presenters discuss chronic disease wellness, healthy lifestyle and prevention. Testing and men’s program promotion are partnered with local LGBT organizations to maximize our outreach to gay men in gay-friendly venues including local bars, festivals, and media.

Southwest Center’s women’s prevention programs are partnered with domestic violence prevention organizations, local domestic violence shelters, and homeless shelters. It took a year of planning, hiring and training to build the program with the partnering organizations. We hired

capable women who are committed to the cause and trained to conduct HIV testing and present programs at the shelters. We seek to be an international exemplar in the area of partner violence prevention through educating women and men about the very high correlation between partner violence and chronic diseases and in particular, HIV and sexually transmitted diseases (STDs). Through our women's support group feedback, we found that more than 95 percent of HIV-positive women who attend Southwest Center's programs have reported experience with domestic violence, threats of violence, and sexual coercion.

Youth HIV prevention initiatives are readily funded through private foundations focusing on youth at-risk. Southwest Center reaches out to educate high-risk youth through a classroom-based program called Positive Peer Prevention or P3, partnered with Arizona's state department of education. Youth prevention curriculum was developed by Southwest Center staff, approved by the State Department of Education. We provide several presentations in public and private schools each week. There is no particular method of scheduling the school-based workshop. Invitations may come from school principals, counselors, nurses, and faculty members who teach health and related subjects.



Furthermore, Southwest Center has hosted a five-year Youth Empowerment Program (YEP), partnering with two other organizations helping to reach LGBT and Native American youth (1N10 and Native Health). More than 60 at-risk youth attended this after-school program which included curriculum designed to build self esteem and health choices among the attendees. Funded by the CDC, this three-way partnership helped reach youth of color in ways not possible for any one youth organization alone.

We lead a program for HIV-positive youth in partnership with Phoenix Children's Hospital. The weekly program helps teens who are HIV-positive from birth make the difficult transition from adolescence to adulthood. A support and summer camp helps HIV-positive teens learn how to make their own doctor appointments, stay adherent to medications, and make healthy choices in order to live well and further prevent the spread of HIV/AIDS.

Finally, Southwest Center's annual summer camp for entire families who are impacted by HIV/AIDS – Camp Incredible – is funded by a variety of community-based retail, private foundations and individual donors. For several hundred participants, this often is the first time the family has experienced a vacation or time away as a family to relax and support each other. Camp Incredible is partnered with and staffed by physicians and medical staff from the McDowell Healthcare Clinic – our primary care partner – as well as with Phoenix Children's Hospital.

## **Chronic Disease Wellness and Community Engagement**

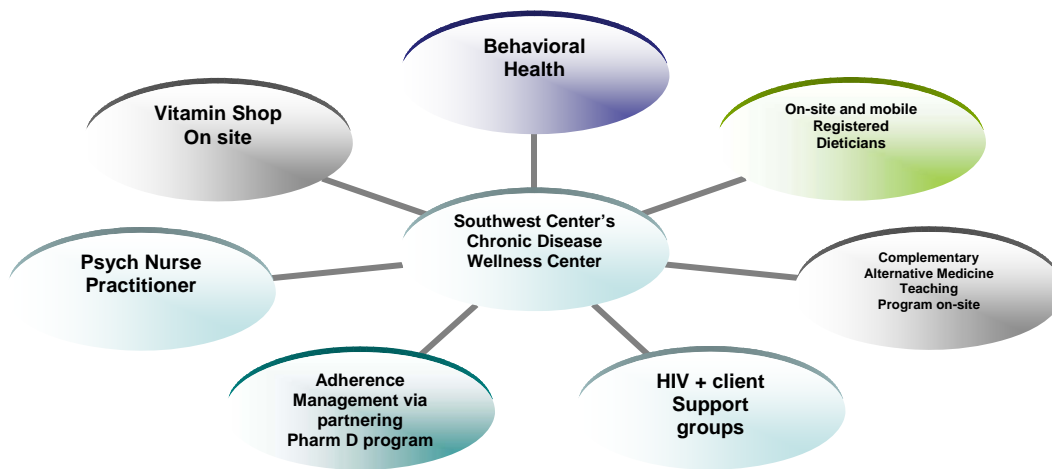
Prevention programs alone cannot address the distinct needs for chronic disease support faced by those impacted by HIV/AIDS. Southwest Center's Wellness and Life Management Program helps people who are impacted by HIV manage their disease and live the most healthy, productive lives possible.

At any given time, more than 1,200 individuals impacted by HIV/AIDS are assisted at Southwest Center by licensed professionals who are trained specifically in HIV knowledge, including licensed behavioral health counselors, registered dieticians, and naturopathic physicians and other services. Medical massage and other wellness support services will be added in 2012.

Providing chronic disease wellness support that goes beyond the rubric of core primary care is a difficult proposition when most of the wellness services are not covered by private insurance or public health reimbursement. The goal at Southwest Center has shifted from providing a lifetime of wellness services, to *helping clients help themselves* by learning *how* they can take responsibility for learning about their health and then, living a life of wellness.

In the early years, nearly \$1 million in government funding supported wellness initiatives at Southwest Center. As government funding decreased for many of these services as the shift to primary care progressed in 2006 and beyond, Southwest Center created an innovative model of community engagement to engage healthcare students from nearby college programs. We offer teaching partnerships with institutions of higher education to provide naturopathic physician, acupuncture, medical massage and nutritional support for those who need to understand how to take care of themselves and seek support when not feeling well. While we provide administrative support for appointment setting, students serve clients and gain experience under the watchful eye of their licensed instructors.

Each institution of higher education is under contract with Southwest Center so that roles, goals of the program to benefit both clients and students, expectations of quality service, and liability issues are clearly spelled out in a written legal contract. We established student rotations to provide naturopathic/complementary alternative medicine wellness support, acupuncture, medical massage, meditation/relaxation and healing-related services. As noted in Figure 4 on page 16, services provided including nutrition and acupuncture by our professionals help to offset the negative side effects of HIV prescription medicines.



**Figure 4: A comprehensive array of wellness support services that complement primary care at Southwest Center for HIV/AIDS**

As HIV/AIDS Wellness trends evolve, Southwest Center has plans to create broader-based chronic disease management programs that can be used to support other chronic diseases. We will continue to develop our behavioral health consortium of outsourced private practitioners, and with funding, will continue to provide nutritional support through our consortium of outsourced dieticians. Services are likely to include telephone and web-based support regarding how to cope and thriving with chronic disease, medication adherence, healthy lifestyle, smoking cessation, back-to-work support, life skills/life planning/financial planning support and estate planning.

Southwest Center’s community outreach team includes nearly 100 innovative, community-based partnerships and more than 300 volunteers who help Southwest Center serve clients and reach out to educate people about HIV/AIDS, including students in public schools, universities, hospitals, domestic violence and homeless shelters, and organizations reaching at-risk and underserved populations.

By strategically identifying community partners and by targeting local leaders who can become ambassadors for fighting HIV/AIDS, Southwest Center has reduced barriers to populations who traditionally have been traumatized by stigma. Some of our partnerships offer highly active forms of interaction, such as co-produced programs. Some of our partnerships provide more “passive collaboration” as referral sources, opening new doors of research, prevention and wellness that otherwise would not be possible.

What determines an effective community partnership? In order to be strategic about selecting community partners, Southwest Center must know and stay true to its core mission and strategic direction. This requires us to regularly assess and determine the following things.

1. What do we do really well – and better than our competitors or existing providers?

2. After assessing our strengths as well as our weaknesses, what strengths do other organizations have that could help complement Southwest Center's strengths in order to best serve clients' needs?
3. How can we ensure that we are partnered with primary care to create a medical home model?
4. How can we maximize our community space to enhance delivery of our services?
5. How does each part of our mission foster community engagement?
6. How can we prioritize community collaborators in order to better each groups, reduce stigma?

As of today, Southwest Center's initiatives all require community engagement and community-based partners. The list below illustrates many examples of community collaborators needed.

<b>Research Partners</b>	<b>Prevention Partners</b>	<b>Chronic Disease Wellness Partners</b>	<b>Fundraising Partners</b>
<ul style="list-style-type: none"> <li>✓ Clients</li> <li>✓ Medical doctors</li> <li>✓ Clinical research community</li> <li>✓ HIV/AIDS clinics</li> <li>✓ Pharmaceutical companies</li> <li>✓ Donors/funders</li> <li>✓ Universities</li> <li>✓ Hospitals</li> <li>✓ Institutions of higher education (community colleges, trade/professional colleges)</li> <li>✓ Ethnic-based organizations (<i>Hispanic, Black, Native American, Asian Pacific Islander</i>)</li> <li>✓ Bioscience and research-based organizations</li> <li>✓ Nonprofit partners</li> <li>✓ Clients for advocacy</li> <li>✓ Elected officials</li> </ul>	<ul style="list-style-type: none"> <li>✓ Clients</li> <li>✓ Families</li> <li>✓ Donors/funders</li> <li>✓ Other ASOs</li> <li>✓ Government agencies</li> <li>✓ Pharmaceutical companies</li> <li>✓ Corporate orgs</li> <li>✓ Health agencies</li> <li>✓ Volunteers</li> <li>✓ Ethnic-based organizations (<i>Hispanic, Black, Native American, Asian Pacific Islander</i>)</li> <li>✓ Nonprofit partners</li> <li>✓ Clients for advocacy</li> <li>✓ Elected officials</li> </ul>	<ul style="list-style-type: none"> <li>✓ Clients</li> <li>✓ Families</li> <li>✓ Medical community</li> <li>✓ Donors/funders</li> <li>✓ Other ASOs</li> <li>✓ Government agencies</li> <li>✓ Pharmaceutical companies</li> <li>✓ Corporate orgs</li> <li>✓ Health agencies</li> <li>✓ Volunteers</li> <li>✓ Ethnic-based organizations (<i>Hispanic, Black, Native American, Asian Pacific Islander</i>)</li> <li>✓ Nonprofit partners</li> <li>✓ Clients for advocacy</li> <li>✓ Elected officials</li> </ul>	<ul style="list-style-type: none"> <li>✓ Government grant funders</li> <li>✓ Private foundation donors</li> <li>✓ Individual donors, major gifts</li> <li>✓ Individual donors – annual campaigns and smaller donations</li> <li>✓ Special event fundraising</li> <li>✓ Community-based events at grassroots level</li> <li>✓ Volunteers</li> <li>✓ Clients for advocacy</li> <li>✓ Elected officials</li> </ul>

### **Fundraising and Community Engagement**

In order to fund services to clients who predominantly cannot afford to pay for medical and support services, Southwest Center is required to have a very diversified portfolio of funding sources. No AIDS service organization can afford to base the funding of operations upon one or two grant or funding sources – these risky funding models spell disaster if the primary funding source goes away.

Southwest Center has cultivated strong funding partnerships among its base of more than 8,000 private donors, more than 100 private foundation organizations, and its government funding

sources (federal, state, county and local/municipal agencies). We are steadily improving our ability to measure outcomes and adhere rigorously to the terms and conditions of each grant contract – something still relatively new for ASOs as funding requirements have tightened. We also conduct three local events which are very large in scope – our formal dinner gala, our Dining Out For Life day in partnership with local restaurants (part of an international event) and our home tour, partnered with local interior designers. Altogether, these fundraising activities bring approximately \$1 million to Southwest Center’s budget in support of our programs for men, women and youth.

## **Closing Thoughts**

In an era where traditional government funding has been cut for HIV support services in efforts to focus on primary care core services. ASOs must continue to offer the warmth and community-based support that creates a safe, warm and welcoming place where the population of those at-risk and impacted will feel supported and nurtured. Yet, ASOs must also continue to evolve in its public health work. Staff must be competent, caring, and capable of collecting data and completing the immense amount of paperwork required to run an agency-like organization that reports like a bureaucracy but behaves like a caring best friend. The work will never end. There are no one-size-fits-all, “cookie-cutter” approaches that serve all communities.

For more than 15 years, Southwest Center has helped to create a one-stop model for healthcare service partnered with primary care. We have been co-located with a large primary care clinic in Phoenix, Arizona, offering one-stop services for health and support services. Today, the co-location expects to expand to include programming that leverages both agencies’ program offerings, meeting the needs of underserved clients. In future years, service may expand to encompass HIV and co-morbidity diseases and other chronic diseases.

Southwest Center is continually learning about our community’s needs and forging vital partnerships in order to provide research, prevention and chronic disease wellness support for those impacted by HIV/AIDS. Using practical knowledge and community-based research, Southwest Center will continue to maximize the impact of its service to clients through effectively managing community-based partnerships and seek new opportunities for collaboration.

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Carol A. Poore received her Ph.D. in Public Administration from Arizona State University. Her primary field of research focuses on social networks and downtown community revitalization driven by social capital, using case studies from urban projects across the United States. Dr. Poore is president and CEO of Phoenix-based Southwest Center for HIV/AIDS, the oldest and largest nonprofit HIV/AIDS service organization in the U.S. Southwest providing a unique combination of clinical trial research, prevention, and wellness support services. Southwest Center has helped bring 29 of the available 32 HIV/AIDS medications to market through its 17-year clinical trial program.

From 2002 to 2007, Poore served as vice provost of public affairs at Arizona State University's West campus, overseeing a department responsible for all aspects of community outreach and fundraising. As a senior administrator for the largest U.S. public university, she provided leadership for four colleges and a campus that doubled in size, growing from 4,500 to more than 9,000 students during her tenure. Dr. Poore earned her master's degree in business (MBA) and holds a Bachelor of Science degree in Broadcasting and Journalism from ASU. Her book, "*Building Your Career Portfolio*," was published in 2001 by The Career Press and is available in English, Korean, and German languages worldwide.

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