Positive Wellness

A Guide to Native-Specific Linkage to Care

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Acknowledgements

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We are so grateful for the wisdom and support of our ancestors,

who live on in our elders, our relations and our children.
May we carry forward in a good way with their blessings.

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As a gay or two-spirited man living with HIV, the positive relationships that I have built with my providers have meant everything. They've had a significant impact on me living a healthy 27 years with this disease.

-- Tommy Chesbro, *Cherokee/Lumbee*

I. Introduction

POSITIVE WELLNESS is a time-limited, individual-level intervention to link Native people who have recently been diagnosed with HIV to appropriate medical care. It was adapted by the National Native American AIDS Prevention Center (NNAAPC) from the Centers for Disease Control and Prevention's (CDC) linkage to care (LTC) model, *Anti-Retroviral Treatment and Access to Services (ARTAS)*, incorporating Steps Toward Change (STC) behavior change model.

ARTAS and STC have many promising aspects that are applicable in Native communities, including using a strengths-based, client-centered approach. *POSITIVE WELLNESS (PW)* takes the basic ARTAS approach and integrates cultural strengths and Native views of health and holistic wellness. It also incorporates the best of both behavioral and biomedical approaches to HIV wellness in a broader cultural perspective. By extending, and in some cases rethinking mainstream approaches, Linkage Coordinators (Positive Wellness Counselors) can better address the challenges their Native clients may face. *PW* targets key challenges and potential barriers to care, including lack of knowledge of benefits of care, difficulty navigating health systems; historical and personal trauma; mistrust of Western medicine; and exclusion of traditional approaches. By addressing such barriers with a strengths-based approach, Native communities can reframe the way we conceive of and meet these challenges, and direct our cultural and communal power towards overcoming them.

The importance of linking to care cannot be underestimated, especially in Indian Country, with American Indian/Alaska Natives having the shortest survival rates after an AIDS diagnosis. Studies show those who link with care soon after an HIV diagnosis have better health outcomes, are more likely to adhere to medication regimens, and ultimately are less likely to transmit the virus to others. However, current efforts do not often take into consideration the realities of the lives of Native clients and their communities. Often, Native clients face a more complex navigation through necessary services, and are not always met with culturally informed counseling. The goal of *POSITIVE WELLNESS* is to facilitate much needed awareness and education, self-efficacy and access to medical care in a culturally appropriate manner.

POSITIVE WELLNESS focuses on HIV and AIDS counseling and linkage to care, but the framework, skills and cultural approaches are applicable to all areas of health (diabetes, obesity, tobacco, physical activity, aging, etc.)

Intended Audience

POSITIVE WELLNESS is designed for those working in health professions who are responsible for providing culturally competent and comprehensive health services to American Indian, Alaska Native, and Native Hawaiian people. As the program is not a short term program, providers of *PW* should be able to commit to working with a person over the period of 5-8 weeks, at a minimum. As a culturally responsive and strengths-based approach, *PW's* focus on trust building and engaging clients in medical care can easily be translated into other health areas.

A Note About Gender Language Used in This Manual

This publication was created with both gender and cultural responsive language to include cultures that have more than two gender identities, as well as gender non-conforming individuals and those who do not wish to gender identify. All pronouns are gender neutral – they, them, their – to break out of the more constrictive binary gender and normative language of he/she, him/her and his/hers.

II. Why Linkage to Care Matters in Indian Country

In July 2010, The White House released the first ever National HIV/AIDS Strategy (NHAS), which called for a renewed and slightly restructured focus on HIV prevention and care efforts. The three primary goals of NHAS are to reduce the number of people who become infected with HIV, increase access to care and improve health outcomes for people living with HIV, and reduce HIV-related health disparities (Office of National AIDS Policy, 2010). Then in 2011-2012, the CDC launched High Impact Prevention (HIP) as a new initiative guiding HIV prevention and treatment. The aim of this framework is to target communities most impacted by the epidemic, and to ensure resources are being used as effectively as possible. By combining scientifically proven, large-scale prevention methods and targeting geographic areas with the highest risk, High Impact Prevention aims to bring an end to the epidemic. These initiatives currently provide an overall picture of the current state of the epidemic. High Impact Prevention and NHAS seek to create a more streamlined HIV prevention system that is more cost-effective and efficient. With game changing vaccine research and the increasing benefits of HIV medications, linkage to care (LTC) is a vital component of high impact HIV prevention and treatment.

Despite our small numbers compared to other racial and ethnic groups, the potential impact on our communities is great. Only three people in a single community who die from complications due to HIV can mean the loss of a clan mother, a ceremonial leader or the last fluent speaker of the language. By the same token we may be able to have a meaningful impact on our communities by using some very focused key strategies, tools and programs advocated for by High Impact Prevention. Our mindfulness and intent in the current era can also lay the foundation of health for future generations.

What is Linkage to Care?

Linkage to Care (LTC) can be defined as any service that works to support a person as they actively engage with the medical care community – hopefully for an extended period of time. In the area of HIV prevention and care, we refer to linkage to care as the process of working with a newly diagnosed person with HIV (or a person that has fallen out of care) to make and maintain regular medical appointments for the purpose of accessing medical guidance and disease monitoring care.

The CDC created *ARTAS* (*Anti-Retroviral Treatment and Access to Services*) – one of the first structured interventions for linking people to care. This effort is only one model being developed to ensure timely and effective linkage take place. However, many Native people are not being linked to care or are not accessing this care soon enough to stop the progression from HIV to AIDS. *POSITIVE WELLNESS* is an adaptation of the *ARTAS* model that accounts for the cultural distinctiveness and service delivery realities of many Native communities.

Relevant Linkage to Care Data

One of the most powerful Western tools we have in the fight against the spread of HIV and the progression to AIDS is Antiretroviral Therapy (ART). Highly active antiretroviral treatment for AI/AN individuals leads to higher CD4 counts and improved survival rates. (Gorgos et al., 2006). On the community level, early diagnosis and initiation of medical treatment reduces viral load in AI/AN communities (Gorgos et al., 2006)

The latest data from the CDC, indicate not only a rise in numbers of new diagnoses, but also call to service providers and tribal health organizations to prioritize efforts to link individuals to care as soon as possible after test results come back reactive.

Of persons who were diagnosed with HIV, fewer American Indian/Alaskan Natives survived, with only 88 percent living longer than 3 years (CDC, 2012). This is the shortest survival rate out of reported racial/ethnic categories. Co-occurring factors that may contribute to this alarming rate are:

- 70 percent initial dual diagnosis HIV and AIDS – the highest rate of all reported races and ethnicities (CDC, 2013a)
- Only 75 percent of American Indian/Alaska Native (AI/AN) individuals (13 years or older) who found out they were living with HIV in 2010 were linked to medical care within 3 months – the lowest percentage of any group. (CDC, 2013a)
- Only 33 percent of American Indian/Alaska Native (AI/AN) and 44 percent of Native Hawaiian individuals (13 years or older) who were diagnosed with HIV in 2008 had undetectable viral loads by the end of 2009 – these are the 3rd and 4th lowest rates compared to other reported races/ethnicities. (CDC, 2013a)

In short, HIV infections are rising and Native people are dying faster from the disease. These numbers are troubling. When these statistics are viewed next to the CDC's report that new HIV infections among AI/AN people increased by 8.7% from 2007 to 2010, it is becoming apparent we as Native people need to continue and renew efforts to meet the needs of Native individuals newly diagnosed and living with HIV. (CDC, 2012)

Many of the same challenges and cultural contexts exist whether we are looking at preventing new infections or maintaining health after contracting HIV. In a 2013 factsheet on HIV/AIDS among American Indian and Alaska Native (AI/AN) people, CDC identified the following specific prevention challenges and risk factors for Native communities:

Race and ethnicity are not, by themselves, risk factors for HIV infection. However, AI/AN are likely to face challenges associated with risk for HIV infection.

- **Sexually transmitted diseases (STIs)**. AI/AN have higher rates of chlamydia, gonorrhea, and syphilis than whites and Hispanics/Latinos and are second only to blacks/African Americans, who have the highest rates for all three STIs. STIs increase the susceptibility to HIV infection.
- AI/AN self-identified gay, bisexual and two-spirit men may face **culturally based stigma and confidentiality issues** that may limit opportunities for education and HIV testing, especially among those who live in rural communities or on reservations.
- **Cultural diversity**. There are 566 federally recognized AI/AN tribes, whose members speak some 200 languages. Because each tribe has its own culture, beliefs, and practices and these tribes may be subdivided into language groups, it can be challenging to create culturally appropriate prevention programs for each group. Tribal and cultural differences regarding gender and sexuality within the AI/AN community must be considered in developing culturally appropriate prevention strategies.
- **Socioeconomic issues**. Poverty, including limited access to high-quality health care, housing, and HIV prevention education, directly and indirectly increase the risk for HIV infection and affect the health of people living with and at risk for HIV infection. Compared with other racial/ethnic groups, AI/AN have higher poverty rates, have completed fewer years of education, are younger, are less likely to be employed, and have lower rates of health insurance coverage.
- **Mistrust of government and its health care facilities**. The federally funded Indian Health Service (IHS) provides health care for approximately 2 million AI/AN and consists of direct services delivered by the IHS, tribally operated health care programs, and urban Indian health

care services and resource centers. However, because of confidentiality and quality-of-care issues and a general distrust toward the US government, some AI/AN may avoid IHS.

- **Alcohol and illicit drug use**. Substance use can lead to sexual behaviors that increase the risk of HIV infection. Although alcohol and substance abuse does not cause HIV infection, it is an associated risk factor because of its ability to reduce inhibitions and impair judgment. Compared with other racial/ethnic groups, AI/AN tend to use alcohol and drugs at a younger age, use them more often and in higher quantities, and experience more negative consequences from them.
- **Lack of awareness of HIV status**. Overall, approximately one in five (18%) US adults and adolescents living with HIV infection at the end of 2009 were unaware of their HIV infection. However, a greater percentage of adult and adolescent AI/AN (25%) were estimated to have undiagnosed HIV infection at the end of 2009. This translates to approximately 1,100 people in the AI/AN community living with undiagnosed HIV infection at the end of 2009.
- **Data limitations**. Racial misidentification of AI/AN may lead to the undercounting of this population in HIV surveillance systems and may contribute to the underfunding of AI/AN-targeted services. (CDC, 2013)

Data aren't the whole story, however, and successes in the fight against the HIV epidemic in Indian Country have come through individual agencies, community organizations, tribes and people going off the grid, and working from experience and wisdom that comes from diverse sources. Ancestral understanding, discussion and consideration, traditional teachings and holistic thinking all contribute to decision making that asks what we can learn from past generations and what we hope to leave for our future generations. We cannot just create hotspot answers to small questions without also working to make our communities healthier places in which to be born, grow, live and share with our families. We must always ask those bigger questions of health and wellness in every aspect of life and not focus only on the particular circumstances that led to contracting a virus like HIV.

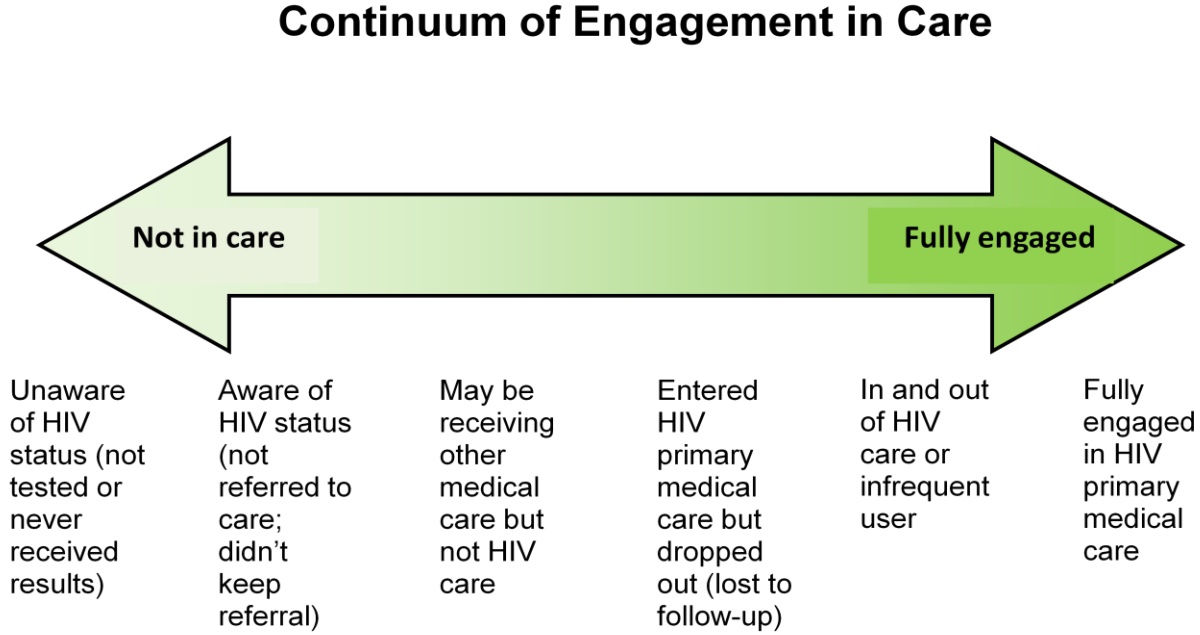
III. Linkage to Care and Case Management

Linkage to care (LTC) is one important avenue by which Native-serving health organizations can help improve health outcomes for HIV-positive Natives. It is building a bridge between prevention services (which have historically included HIV testing) and care. It is becoming a normal part of routine health care from testing to treatment. While LTC is usually intended to be short-term case management, it may include long-term follow-up, especially in smaller towns and reservations, where service providers and care givers have built strong relationships within the community. There are many reasons for this, including the position of trust many PW Counselors and testing counselors take on. They are often a go-to person, who can help case managers and clinical staff connect with clients. Linking to care can also be an additional set of duties for someone who is already the testing, counseling and referral services process, and can therefore be successfully integrated into existing programs.

Focused efforts to link Native individuals to care and effective treatment helps ensure they do not fall through the cracks of a very complex system – meeting eligibility requirements, tribal membership requirements, multiple steps and care providers who may not be in the same building or same town. It's an uphill battle even for those who are familiar with systems. Many Native people living with HIV/AIDS (NPLWHA) have little or no experience navigating the labyrinth of paperwork, regulations and phone calls. More than anything, it is a matter of knowing where to go, which is one essential function of an LC.

Issues of stigma, shame, fear, homophobia and other can also be a hindrance. These factors add up quickly and can lead to individuals shutting down and tuning out. The result is a population of NPLWHA who are left out at every level, and frequently live without health care, find systems threatening, feel hopeless, continue to use substances and die prematurely.

Diagram 2:



Source: Cheever, LW. Engaging HIV-infected patients in care: their lives depend on it. Clinical Infectious Diseases *2007; 44: 1500-1502.*

If we look at engagement in care as a continuum from not in care to fully engaged (Diagram 1), we can identify specific areas where testers, risk counselors, patient navigators, linkage coordinators, case managers and care providers are the face of care for potential clients/patients. Client-centered, strengths-based approaches require that we look at this continuum, not as where the client has failed to engage, but where we, knowing the challenges that face HIV-positive individuals, can find ways to help make engagement easier, more culturally informed and effective.

Another important group of HIV-positive individuals are those who re-engage in care. And for AI/AN/NH populations, who have a high drop-out rate and delay in both diagnosis and seeking care, re-engagement efforts are especially important to consider in outreach, education and programs such as ARTAS and *POSITIVE WELLNESS.*

The HIV Treatment Cascade

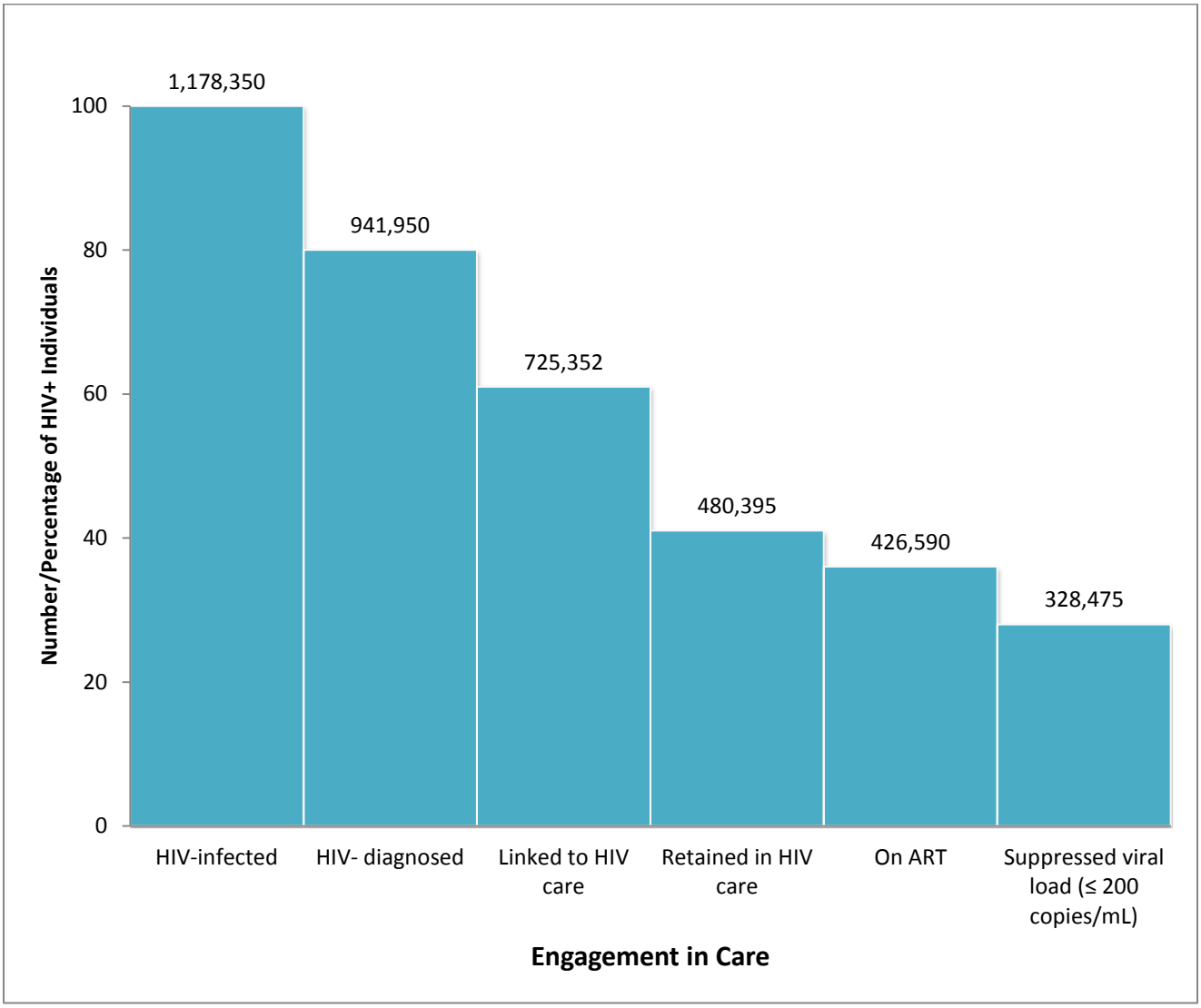
Data on current interventions also point to the need for improvement in how we address the HIV epidemic overall. In 2011, Gardner, et.al. released research findings regarding the state of HIV care and treatment in America, and gaps that exist in working with those people living with HIV to benefit from modern biomedical treatment options. Out of all of the individuals living with HIV in the U.S., only 80% are aware of their status, 62% have been linked to care, 41% stay in care, 36% get antiretroviral therapy, and only 28% are able to achieve an undetectable viral load (defined as ≤200 copies/mL) by adhering to their medication regimens. For American Indians/Alaska Natives, the number of those who have an undetectable viral load is only 25% -- the lowest of any reported race/ethnicity (Gardner, 2011).

Ideally, all those who are HIV-positive would know their status, engage in appropriate care, and be able to keep their viral load low so they may enjoy a long and healthy life. But, the numbers indicate that at each step in the process, people are lost to care and are less likely to reap the benefits of current medical and wellness interventions. However, each drop in numbers also indicates where we can intervene by creating more effective ways to reach out to people.

Testing – Individuals know their status, and know the status of their partners
Linking to care – Referral or seeking out HIV care in addition to other health care issues clients may have
Retention in care – HIV care is a lifelong commitment
Adherence to medication – Being able to and choosing to maintain medication schedule(s)

We also know that with each step, more individuals have better health outcomes. At the right end of the chart, we see that most of those who do stay in HIV care and adhere to medications can reduce their viral loads significantly.

Diagram 3: HIV Treatment Cascade



Source: http://blog.aids.gov/2012/07/hivaids-treatment-cascade-helps-identify-gaps-in-care-retention.html#sthash.nquB2cil.dpuf

Where does Linkage to Care Fit In?

It is easy to see where linkage to care fits in when you examine the Treatment Cascade. However, as a program, tribal entities, health departments and community-based organizations (CBOs) need to ask themselves, "Where does this fit in with the programs we currently have up and running?" Linkage to care programs, such as *POSITIVE WELLNESS*, are time limited programs that actively work one-on-one with people recently diagnosed with HIV to explore the best avenues to take to get them linked to an appropriate medical provider. *POSITIVE WELLNESS* is designed with at the most seven sessions, however, there are other programs that work one on one with people living with HIV/AIDS as well – such as comprehensive risk counseling and services (CRCS) and Ryan White case management. However,

even though there may be some overlap in terms of client population, and nature of services developed, all three of these programs have distinct purposes

Linkage to Care (i.e. *POSITIVE WELLNESS*)

- People living with HIV or AIDS
- Facilitates acceptance
- Time-limited
- Intensive
- Goal is to connect to the medical system
- Identify and focus on strengths
- Small case loads
- Not a replacement for Ryan White or CRCS, meant to augment
- Happens before medical case management
- Is open to those re-engaging in care

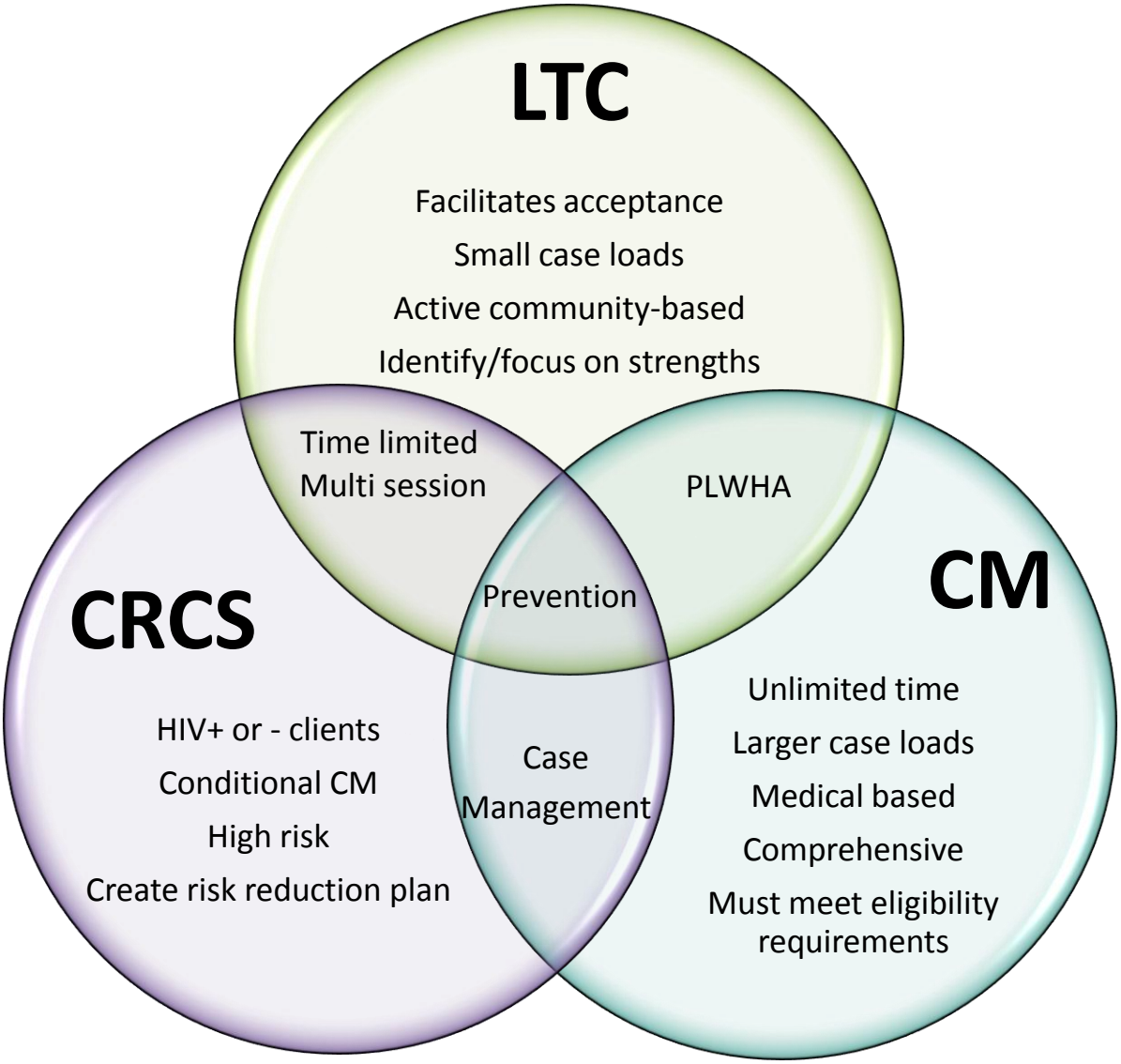
Comprehensive Risk Counseling and Services - CRCS

- Time-limited, but can be longer term
- People living with HIV/AIDS, high risk negatives, or people of unknown serostatus
- High risk for acquiring or transmitting HIV
- Uses a comprehensive risk-reduction plan
- Ongoing, multi-session
- Conditional case management services

Medical Case Management (e.g., Ryan White, Ahalaya)

- Not time bound
- Long-term
- Comprehensive wrap-around services
- For people living with HIV or AIDS
- Requirements (i.e., income and residency requirements)
- Large caseloads
- Medical-based

Diagram 4: Where does Linkage to Care fit in?



IV. The *POSITIVE WELLNESS* Model

Behavioral Determinants

The Centers for Disease Control and Prevention developed *Antiretroviral Treatment and Access to Services (ARTAS)* with an eye toward bridging the gap between testing, and treatment and prevention through early biomedical intervention. Research showed three major factors kept people from accessing treatment after testing:

1. Lack of knowledge
    a. Clients lacked an understanding of the benefits of linking to care soon after diagnosis.
    b. Clients lacked the knowledge and skills to navigate the appropriate health systems.
2. Low self-efficacy – Even with some knowledge of why and how to seek care, many clients did not confident in doing so.
3. Low outcomes expectations – Many clients who delayed medical care reported they did so because they did not feel medical care would really help them or their health.

POSITIVE WELLNESS is an adaptation of the *ARTAS* program, and as such works with the same general framework as *ARTAS*. In addition to the three factors listed above, NNAAPC believes that the following also serve as barriers for people accessing treatment after HIV testing:

1. Lack of knowledge of HIV/AIDS
2. Lack of knowledge about the healthcare system and resources available to them
3. Lack of trust/confidence in the medical system
4. Low outcome expectations - Many clients are expecting a poor interaction with medical providers
5. Lack of self-efficacy to discuss their HIV status and health with a medical provider
6. Lack of social support

Core Elements

In light of these potential barriers to care, *ARTAS* was developed and tested based on five core elements:

1. Build an effective working relationship between the Linkage Coordinator and each client.
2. Focus on the client's strengths by encouraging each client to identify and use his/her strengths, abilities and skills to link to medical care and accomplish other goals.
3. Facilitate the client's ability to identify and pursue his/her own goals, and develop a step-by-step plan to accomplish those goals
4. Maintain a client-driven approach by conducting between one and five sessions with each client, conducting active, community-based case management by meeting each client in his/her environment and outside the office, whenever possible; coordinating and linking each client to available community resources based on client's needs; and advocating on each client's behalf, as needed, to link that person to medical care and/or other needed services.

From the beginning of the HIV pandemic, issues of historical mistrust, difficulties accessing appropriate care and lack of culturally competent services have been ongoing challenges in Native communities and for individuals seeking care. With their emphasis on increasing knowledge, self-efficacy and client trust, *ARTAS* goals and core elements seem to be a good foundation for building a successful and much needed linkage to care model for Native-serving clinics and other health organizations. The *POSITIVE WELLNESS* adaptation draws upon the tenets of these original five core elements and adds some additional elements as well.

1. Build an effective working relationship between the PW Counselor and each person served.
2. Focus on the participant's strengths by encouraging each participant to identify and use his/her strengths, abilities and skills to link to medical care and accomplish other goals.
3. Facilitate the participant's ability to identify and pursue his/her own goals, and develop a step-by-step plan to accomplish those goals
4. Maintain a client-driven approach by conducting between one and seven sessions with each participant, conducting active, community-based case management by meeting each participant in their own environment and outside the office, whenever possible
5. Coordinate and link each participant to available community resources based on participant's needs
6. Advocating on each participant's behalf, as needed, to link that person to medical care and/or other needed services.
7. Facilitate the identification of viable sources of social support

The three defining features of the intervention are:

- Building effective, working relationships between the participant and PW Counselor, and between the PW Counselor and community partners
- Focusing on the participant's strengths rather than weaknesses
- Maintaining a client-driven, culturally appropriate approach

The following is a brief summary (that can be provided to PW participants).

Positive Wellness Summary

- Taking time to build trust is essential
- Is culturally and gender responsive
- Participants identify strengths to overcome barriers and challenges
- Uses a holistic view of strengths including cultural, community, individual and family strengths
- Goal is to link to medical care
- Benefits include better health outcomes and reduced transmission
- Assistance is given when appropriate
- Session Plan includes goals and tracks progress and is used as needed
- Location, time and date of the session is mutually agreed upon by participant and counselor
- Transfers participant to other needed services

Theoretical Basis

POSITIVE WELLNESS is a theory-based intervention. *POSITIVE WELLNESS* is based on the Strengths-Based Case Management (SBCM) model. The SBCM model is rooted in Social Cognitive Theory (especially the concept of self-efficacy), which incorporates aspects of Transtheoretical Behavior Change Models (Prochaska & DiClemente, 1986).

Social Cognitive Theory describes the way in which behavior changes as "a continuous, reciprocal interaction between personal (attitudes and beliefs), behavioral, and environmental influences"

(Kalichman, 1998). The theory helps us understand how people learn as a component of behavior change. A core tenet of the theory is that people are more likely to change their behavior or adopt a new one when their self-efficacy (or their personal belief in their ability to do something successfully) is raised – and this can happen through observation, repetition, and practice. An increased likelihood of behavior change will occur, as well, if a person believes that the new behavior will ultimately be beneficial.

The Transtheoretical Model (TTM) (or the Stages of Change Model) is a framework for understanding how and when behavior change occurs. Behavior change is seen as a series of stages that progress toward healthier choices. A person can be anywhere on the continuum of behavior change – from denying the need for change to embracing the change as an integral component of healthy living. A person can be assess and then 'staged' on their readiness to change. Strategies are then put into place to support movement along the change continuum. Approaches based on this model look at ways to guide the client through these stages to their self-identified goals.

One of the TTM-based approaches is the Steps Toward Change Model (STC). *PW* Counselors incorporate STC to encourage clients to overcome challenges and motivate them to own their own health and wellness. This approach, along with a Strengths-Based Approach (see following sections), are the foundations for PW Counselor/client interactions.

Steps Toward Change Model

Steps Toward Change, drawing from harm reduction, recovery readiness and treatment-based philosophies, is an expansive and organic process to encourage clients to become peer counselors and educators. Unlike approaches that foster loyalty to the program or to a modality, this process is grounded in the client's self-directed and independent choices.

The counselor works to build motivation for change through Motivational Interviewing (MI) methods. They develop a trust relationship with the client and focus on building skills, self-awareness and self-efficacy. The goals of STC are to facilitate:

- Awareness of inner change
- Self-awareness
- Ability to make choices and set goals
- Recognition of feelings, identity and self-acceptance

The individual process of change or transformation takes place within a social context. Experiential learning is accomplished among peers, which has many advantages:

- A mirroring process where individuals can observe or experience similarities or contrasts in thoughts, feelings, actions.
- An opportunity to experience oneself in the presence of others, breaking the isolation, fear and shame.
- An opportunity to witness and model a peer transformational process, i.e. efforts, attitude and behavior changes, social relationships.
- Support for the development of alternative social networks that reinforce process of transformation
- Clear parameters of limits for interaction

Logic Model

The following is the logic model for *POSITIVE WELLNESS*

Problem Statement: The target populations for Positive Wellness are HIV-positive Native American men and women over the age of 18 who have been recently diagnosed with HIV (i.e. within the past 6 months), and who are not engaged actively and consistently in HIV care. Clients out of care are not as likely to adhere to their medicines or to monitor their disease progression or their overall health. A well implemented linkage to care program can help ensure positive outcomes by preparing a person to engage with the medical system as a prepared equal, thus empowering them to take control of their treatment, ensure they take steps to promote their health and wellness, and reduce their risk of transmitting the virus to another person. The factors associated with recently diagnosed Native persons not linking to care include their inability to navigate the system to link to medical care, inability to talk openly about HIV with a medical provider, lack of knowledge about HIV/AIDS, lack of culturally appropriate counseling and services, and lack of information and/or resources about how to access care.

Behavioral Determinants ***Corresponds to risk or contextual factors***	**Activities** ***To address behavioral determinants***	**Outcomes** ***Expected changes as a result of activities targeting behavioral determinants.***	
		Immediate Outcomes	**Intermediate Outcomes**
Lack of self-efficacy to navigate the health care system Lack of self-efficacy to discuss their HIV status and health with a medical provider Lack of knowledge about the benefits of medical care early in disease progression Lack of trust in medical and associated services Lack of knowledge about HIV/AIDS Lack of knowledge about	<u>Session 1: Engagement: Foundations of Trust</u> • Build a trust relationship • Provide an overview of all five sessions • Answer client's questions • Complete all required enrollment paperwork • Explain confidentiality practices undertaken by the program and health care providers • Introduce stages of change model to client • Identify personal goal <u>Session 2: Exploring What It Means to Live with HIV</u> • Provide information on HIV • Engage client in discussion on how they feel about their diagnosis • Use client-centered, culturally appropriate counseling strategies • Perform holistic strengths assessment • Use a strengths-based approach to explore progress toward personal goal <u>Session 3: Living in Balance: Health and Wellness</u> • Identify strategies client is using to maintain health and wellness • Discuss the benefits of taking HIV medicines • Identify support systems for client • Use a strengths-based approach to explore progress toward personal goal	Increased self-efficacy to navigate the healthcare system Increased self-efficacy to talk about HIV, behaviors, and health with a medical provider Increased knowledge about benefits of medical care Increased knowledge of HIV/AIDS Increased knowledge about system of care and available resources Increased response	Linkage to medical care Linkage to related care and cultural services Increased trust in medical and associated services

the system of care and available resources Low response efficacy (i.e., clients don't believe going to the doctor will be useful) Low outcome expectations (i.e., expecting a poor interaction with medical providers) Lack of social support	<u>Session 4: Linking to Care</u> • Describe patient rights and responsibilities • Discuss feelings about meeting with a medical provider • Generate a list of questions client would like to have answered • Role play doctor appointment • Explore local medical resources • Assist client with making a medical appointment	efficacy (i.e., client believes visiting a doctor will be beneficial)	
	<u>Medical Appointment : Walk With Me</u> • Attend medical appointment with client, if requested		
	<u>Session 5: New Journey: Final Session</u> • Debrief doctor's appointment • Use a strengths-based approach to explore progress toward personal goal • Review skills learned • Provide final referrals		
	<u>Follow-up</u> • Check in on personal goal progress • Check in on medical care follow up • Check in on social support • Check in with referral follow-up		

Strengths-Based Approaches

Five aspects of this approach are:

- **Assessment:** the practice of obtaining relevant information from the client's presenting needs, internal and external resources, and desires and proposed outcomes of their participation.
- **Planning:** the process of mutually agreeing on goals and objectives, planning activities to address the clients' needs, and developing strategies that help the client help themselves.
- **Linkage:** the process of actively connecting clients to needed services and resources to address clients' needs.
- **Monitoring:** the practice of systematically assessing how well clients are meeting their objectives and reaching their goals within the timeline proposed in the plan.
- **Advocacy:** provide the client support that encourages and influences desired change.

The strengths-based approach (SBA) is commonly used in social work and has a strong theoretical foundation as an effective strategy to build an individual's success. SBA respects client self-determination and recognizes their strengths come from many different aspects of their lives. The approach is client led, with a focus on future goals and strengths the client brings to a problem or crisis, including strengths on an individual, family and community level.

As an adaptation of ARTAS, PW also seeks to address social determinants most commonly influencing health behaviors and outcomes for Native people. Although circumstances vary for individuals, these factors may still influence family life, personal history, or even the whole community in which an individual lives. These social determinants include but are not limited to:

- Historical and contemporary trauma
- Low levels of education
- Substance use and abuse
- Low socio-economic status
- Gender-based violence
- Poor environmental conditions

Strengths-Based Approach to counseling is based on three main assumptions. One is all individuals have abilities and inner capacities. This could mean inner strengths, such as patience or sense of humor, or resources available to them, such as family support or a job that allows flex-time.

When working with Native individuals, this also includes access to communal and cultural strengths, such as strong networks of relations, cultural knowledge, traditional-spiritual beliefs and other cultural strengths in the communities in which they live or where they were raised. Many individuals who have been raised in an urban situation still have a strong connection to a tribal community and identity, and care providers cannot assume what an individual's cultural identity is until it is shared.

These strengths allow the individual to successfully cope with challenges, as well as perceived and existing barriers to meeting their goals in life. This may be seen when the individual is facing a new diagnosis of cancer, Hepatitis C or of course, HIV. Fear, anxiety, financial and time restrictions can create stress for the client, but this may also be a time of personal breakthrough and commitment to working through these challenges. A person, attempting to deal with a difficult diagnosis may also have trouble identifying or acknowledging their own strengths. A positive, realistic counselor can facilitate that self recognition and provide support throughout their sessions together.

SBA is a way of working with clients that has been very successful in improving client knowledge of the benefits of care, navigating the health system needed to get that care, increasing client self-efficacy and raising the expectations of improving health.

Focusing on strengths improves the provider-patient relationship, teaches the patient to advocate for him/herself, decreases denial and limits resistance to care.

Corwin & Bradley-Springer, 2012

Strengths-Based Case Management is a specific implementation of the strengths perspective, through the process of facilitating desired change in individuals. It adds the technique of focusing on client strengths to the primary principles of case management, which are:

- Encourage clients to identify and use their strengths, abilities, and assets to accomplish goals
- Recognize and support client control over goal-setting and the search for needed resources
- Establish an effective working relationship with the client
- View the community as a resource and identify information sources of support
- Conduct case management as an active, community-based activity (Bandura, 1994)

Therefore, behavior change is influenced by: (Freeman, 2004)

- **Information**: Awareness of risk & knowledge of techniques for coping with the environment.
- **Self-efficacy**: Belief in one's ability to control his/her motivations, thoughts, emotions, and specific behaviors.
- **Outcome expectations:** Belief good things will happen as a result of the new behavior.
- **Outcome expectancies**: Belief the results of the new behavior are valuable and important.
- **Social skills within interpersonal relationships:** The ability to communicate effectively, negotiate with others, and resist pressures from others.
- **Self-regulating skills**: The ability to motivate, guide, and encourage oneself and to problem-solve.
- **Reinforcement value:** Reinforcements are the responses to a person's behavior that increase or decrease the likelihood of reoccurrence. Reinforcement value emphasizes the benefits (rewards) produced by adopting a new behavior, instead of the focusing on what is being given up (costs) by adopting a new behavior.

Good sources of information are essential, and in order to make good decisions about their health and well-being, individuals need access to that information. Building health literacy is one of the goals of any successful behavior change intervention or outreach program. NNAAPC's publication, *A Way to Wellness: Finding and Understanding Native-Specific HIV Data*, discusses this aspect of health work and how programs might go about gathering their own data and information from Native-specific sources and within their own organizations.

Education and building self-efficacy are basics to SBAs. It is capacity building at the personal level and has many benefits for the client that could be extended to their family, worklife and community.

The level of a person's health literacy can be used to predict a person's overall health more effectively than examining that person's age, income, employment status, education level or race

American Medical Association, 1999

Health literacy has been shown to improve adherence to medication. In their 2012 study of a large sample of HIV-positive patients living in the New York City area, Nokes, et al, concluded, "Although other factors such as depressive symptoms and lack of social capital impact adherence to ART, nurses can focus on increasing treatment self-efficacy through diverse interactional strategies using principles of adult learning and strategies to improve health literacy."

In ARTAS, the intervention counselor helps the client learn new information, such as the benefits of accessing medical care, and discuss strategies to achieve the client's goals. During sessions, the counselor may discuss strategies to overcome barriers to visiting an HIV care provider. The counselor and client may practice or role-play interactions between the doctor and patient, if that is helpful to the client. These activities help a client's self-efficacy and increase their belief visiting an HIV care provider or linking to medical care can lead to positive outcomes. In the process the client can increase their health literacy – knowing how and why medical may benefit them – and in doing so, become more willing to pursue care.

In contrast, counseling from a deficit model tends to focus on problems, pathologies, deficiencies and reactions rather than skills, abilities, proactive actions and areas of achievement. By taking a deficit view, it is easy to label a person and move forward with our own agenda of what is right for them. This type of interaction is a hallmark of colonization of indigenous peoples. For this reason, it is one of the least appropriate ways to work with Native individuals in a health care setting, and can lead to further mistrust and trauma.

A very good summary of SBA can be found in *Retention in HIV Care: A Guide to Patient-Centered Strategies*, which is listed in the resource section of this manual.

What Strengths Perspective Is and Is Not

Being strengths-based means… figuring out ways to recognize and use genuine individual strengths to allow building onto existing competencies and effectively addressing concerns.

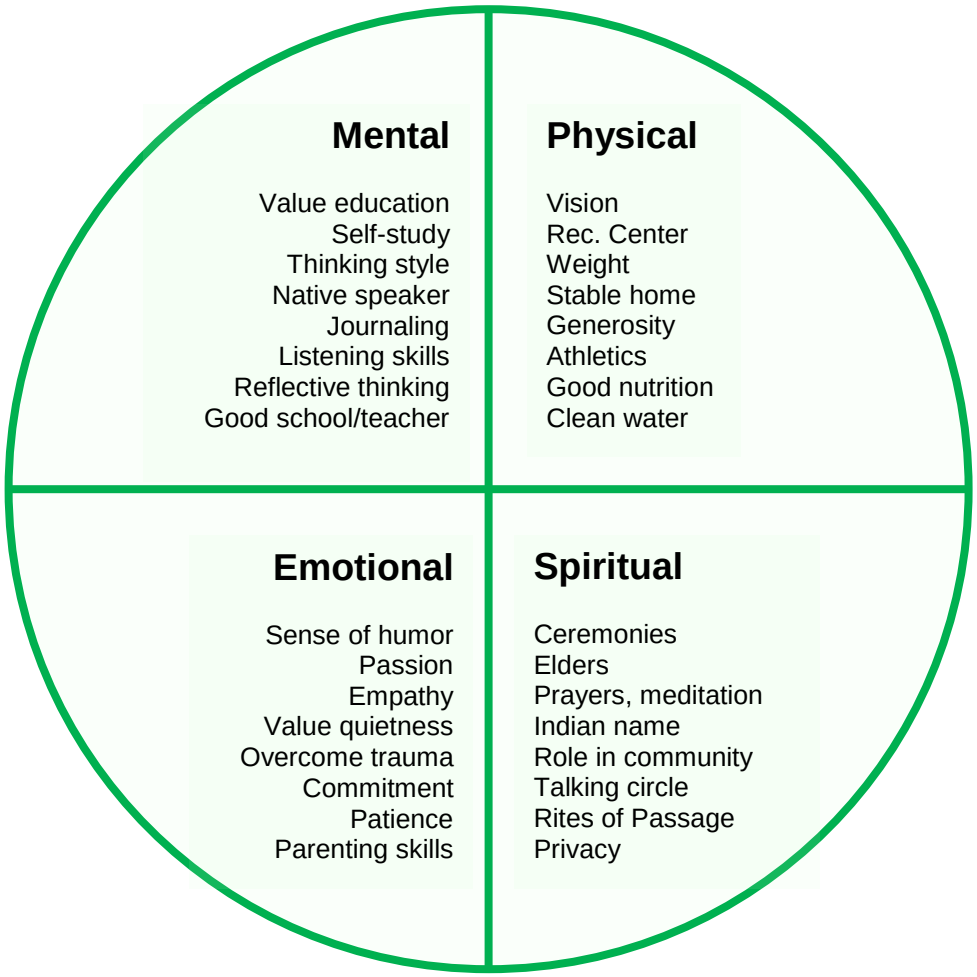
Being strengths-based does not mean… simply focusing on positive aspects and ignoring concerns, or fabricating strengths that do not exist.

A Holistic View of Strengths

Looking at ourselves, our own communities, our cultures and our families from a Native perspective, what strengths do we as professionals have to bring to our work and home life? What strengths do our clients have that stem from not only their personal experience, but where they come from and how they are related to others around them? When we take a holistic view, we are able to not only see where challenges arise, but also ways we can call upon our strengths to meet those challenges. This is an

important process to work through whether we are Native or not, culturally connected or not. Our insights gained from this process will help us in our counseling and facilitating.

Diagram 5: A Holistic View of Strengths
Includes individual, cultural, community and family strengths



The Medicine Wheel has had many variations and is used by a multitude of tribes to discuss wholeness and balance. It is a good framework for a wide view that includes the many different aspects of our lives. The circle contains four parts – Emotional, Mental, Physical and Spiritual. The characteristics given in each section are **examples** of individual or group strengths, which contribute to health and wellness.

Emotional

- Sense of humor – This can also be seen as a sense of perspective, something that helps us let go of fear or hurt. In many indigenous cultures, jokes and teasing are a part of everyday life.
- Passion – Those who have a passion for their traditions, music, their work, cooking or their grandkids could let those passions motivate them through this difficult time (to stick with their medications, for example).
- Empathy – Being able to see the world through another's eyes or sharing in another's emotional experience can lead us to think of others who may be worse off than we are, or who might need our help. By helping others and thinking of others, we can gain perspective into our own challenges.
- Valuing quietness – While some see silence or using a quiet voice as fear or not paying attention, many Native cultures value listening respectfully or taking time to think before responding to a question.
- Overcoming trauma – Our people have survived historical and personal trauma. We have role models and examples from the past we can look to for help facing and working through current trauma. We can honor our ancestors and those around us who inspire us to keep going.
- Commitment – Communal or tribal leadership commitment to the hard issues we face can make all the difference in making HIV testing and treatment available to community members. Individuals can move their families or tribes to create good places for talking circles, health education, and acceptance of LGBTQTS or violence prevention programs.
- Patience – It takes strength to wait for the right time to act, or to accept hurrying through something can lead to mistakes. It takes a certain kind of patience to move from urban time to Indian time and back again.
- Parenting skills – Think of people you know who are good parents. Their strengths come from love, but they may take the form of patience, generosity, confidence or managing priorities well. One way Native people share their parenting skills, even if they don't have biological children is to be that good aunt/uncle or big brother/sister in the extended family.

Mental

- Valuing education, self-study, good school/teachers – Communities, families and individuals who value education appreciate learning new things and sharing their knowledge with others. This could apply to not only school subjects and learning on your own, but also giving and receiving traditional teachings or finding out more about HIV. Teachers are a community asset, and can be valuable allies for health education, HIV presentations in the classroom and breaking down stigmas about LGBTQ and AIDS in the community.
- Thinking style – The way people perceive and remember information. Considering the character of the whole person, not just their test taking abilities or other siloed assessments of intelligence.
- Native speaker – those who can speak their Native language(s) may have ways of understanding the world through concepts that cannot be expressed with American English.
- Journaling – Writing a journal, or keeping a personal blog online can help participants sort through their feelings, tell the story of their journey with HIV, or even be shared with others who might benefit from their experiences.
- Listening skills – Most Native cultures value good listening skills, which are needed in oral traditions. Passing on songs, teaching stories and learning ceremonies are not often written, but must be done in person with the teacher/mentor/elder.
- Reflective thinking – Although space for self-reflection is usually only done in "therapy" settings, PW Counselors can help their participants by allowing time during some of the more intense sessions for this important process.

Physical

- Vision – In many of our Native cultures, visual expressions (paintings, beadwork, sculpture, drawings, etc.) are valued as ways to share information, especially from one generation to the next. Along with oral traditions, visual arts and communication are highly respected.
- Recreation Center – Having a place and opportunity to participate in group sports and athletic activities has been shown to provide many benefits to communities: integrates the disabled, disadvantaged and socially alienated in addition to raising general quality of life, increasing community awareness and civic participation.
- Weight – Although obesity is commonplace in Indian Country, there are some benefits for those seeking intense medical care. Studies have shown cancer patients who are overweight generally fare better than their slenderer counterparts in chemotherapy.
- Stable housing – The concept of home is often different for Native people than for the mainstream. Many have two homes – one in an urban area and one in a rural tribal community. Stability may not always include Western ideals with a separate home for each nuclear family unit, as extended families and relatives may live together. Native homes can be a great source of power, support, comfort and stability.
- Generosity with physical affection or goods - generosity and sharing material things with family, friends and guests is valued and taught throughout the lifetime in most Native traditions. Generosity not only creates a system of reciprocity, but can also be a source of support for those who are living through difficult times.
- Athletics – Even small communities support athletics in and out of school – cross-country running and basketball are popular because they don't require a lot of equipment or infrastructure. Indigenous sports, such as canoeing, lacrosse and wrestling, provide both physical and cultural benefits.
- Good nutrition – Many rural and urban Native groups now promote integrating, or even replacing Western and fastfood-heavy diets with more traditional, indigenous foods – corn, beans, squash, bison, salmon, cranberries, etc. Studies have shown this can lead to great health benefits, especially when combined with regular physical activity.
- Clean water – While many places in the U.S. take for granted clean water supplies, historically and currently, tribal communities struggle against environmental degradation, pollution and toxic contamination of aquifers, lakes, rivers and even rainwater. Many tribes have taken action to improve their rights for good drinking water, as well as healthy ecologies for hunting and fishing. This protective action represents a source of strength and cultural pride.

Spiritual

- Ceremonies – Whether someone goes "back home" to a traditional setting or is part of an intertribal circle in their urban home, connection to ceremonies and ceremonial leaders adds to a person's well being.
- Elders – Elders are usually older tribal members who carry respect, but in many instances, an elder can also be a mature person who has been through many experiences and fulfills communal responsibilities as mentors or teachers.
- Prayers, meditation – These are a common way to bring people together in a circle, begin events and meetings, and are easily adapted to situations where people of many cultures come together. It can also be a highly personal experience that can happen in almost any location at almost any time.
- Indian names – This can help a person maintain their connection to their traditions or extended family. In some traditions it is common to change names with major changes in life, such as leaving home as an adult, being adopted into another tribe, becoming a ceremonial leader or perhaps even living strong with HIV for 10 or 30 years.

- Role in community – From a Native point of view, every person has a role in the community, whether that role comes with a title and teachings, or expectations for fathers, mothers, grandparents and even youth. Everyone has something to add to a community and something to share with others – knowledge, skills, songs, stories, support, physical labor, and the list goes on.
- Talking circle – Rather than attending "support groups," many people seeking help prefer the talking circle model, where everyone has the chance to speak in turn, express and share their experiences as Native people, and connect in a way that includes acceptance without judgment and confrontation.
- Rites of passage – Although this may have been a part of the participant's life in the distant past, having the experience of community acknowledgement of achievement or acceptance into the circle is an important part of a person's life. It may help re-center them as they move forward into a new phase of their life.
- Privacy – Tribal communities often need private or secluded areas for ceremonial structures like sweat lodges and dance arbors. Participants will most likely need a place or space of their own for self-reflection, meditation, solitude or safety.

Culture is Prevention

Diagram 2 is a good depiction of how various components of Native culture can serve as a source of strength and encouragement to pursue healthy paths in life. The important of culture cannot be underestimated or overstated. Some other considerations include:

- Native pride is a strength. Being proud of who you are, your tribe or showing pride for all Native peoples can foster feelings of self-worth and self-regard.
- Family structures can also be a strength. The word family can include others beyond blood relatives – in-laws, people of the same clan, distant relations, others in the community and adopted members.
- When we introduce ourselves to Native clients in particular, it helps to explain membership in a given community and something of who we are as people in relation to others. Though standard counseling techniques often discourage personal disclosure from the counselor, most Indigenous cultural models are based on a system of reciprocity. Offering something of yourself – even a small detail – and orienting yourself in relation to your client can encourage them to open up about themselves and help establish trust. This is a common way Native people introduce themselves and can help establish a respectful, humble and authentic relationship with the client.
- Humility is an appreciated and honored trait. So if you as a PW Counselor do not know something do not pretend to know, or if you would like to know something, be up front and ask for that information. Sharing is mutual.

Cultural Amplifiers

If health providers simply view their Native clients through a deficit lens, it can be difficult to understand some of the underlying factors that have a significant impact on AI/AN/NH health and well-being. A cultural amplifier is "a cultural factor that magnifies the difficulties faced by Native Americans living with or at risk for HIV," (NNAAPC, n.d.). Some of these factors are:

- Circular Migration - unique pattern of moving between urban and tribal communities
- General acceptance of the place for traditional healing methods
- Distrust of authority and the associated bureaucracy and paperwork
- Fear of breach of confidentiality
- Communication style that has been interpreted as "reserved" or "unfriendly" by some who are unfamiliar
- A sense of modesty about bodies that may also keep Native people from discussing sex, sexuality, sexual orientation, especially with someone of a different gender than themselves.

- Family and Community Role – Extended family and community relations are an important basis of Native cultures.
- Orientation to the Present – Many Native communities and individuals experience timeframes, schedules and future goal setting very differently from most Western cultures.
- Mortality – Historically and currently, Native populations have high mortality rates for many diseases, suicides, homicide and vehicle accidents.
- Sexual Orientation and multiple gender identities – Many Pre-Columbian Native cultures recognized more than two gender identities, and had a fluid understanding of sexual behaviors and relationships. This was severely impacted by religious imperialism and conversion.

Not only do these factors influence how Native people access and engage in health care, but also affect the service/care providers and programs available to Natives, especially for a stigmatized health issue like HIV, where these cultural amplifiers can, and do, present challenges and barriers for both Native individual and health provider/counselor.

(A more in-depth discussion of cultural amplifiers and best practices of working with AI/AN/NH clients can be found in NNAAPC's *Clinician's Guide: Working with Native Americans Living with HIV*, which is listed in the Resources and References section of this manual).

Lack of Culturally Appropriate Services and Care

Cultural amplifiers can discourage a person seeking and engaging in services, even when appropriate care is available. Challenges and obstacles to using care can stem from the care process rather than lack of access issues. Studies have shown "lack of culturally sensitive providers, lack of "fit" between service and world view of patients, and general lack of services are often argued as being key obstacles to service utilization for American Indians" (Duran, Duran, & Brave Heart, 1998; Robin et al., 1997; Sontag & Schacht, 1993).

Mainstream approaches to counseling, often designed without data from or consideration of Native populations, may perpetuate the idea that no special considerations should be made for potential Native clients, even when implemented in Native communities. Taking a culturally appropriate perspective may necessitate challenging the idea Native people are helpless without Western medicine. Health care providers, researchers, civic leadership and policy makers should have access to culturally relevant information in order to create more positive and, hopefully, effective health care services and products. But, they cannot make decisions based on a deficit model.

"While the analysis of Aboriginal health emphasized indicators of disease and death, there was much to report that was positive: lower rates for long-term lifestyle-related illnesses, such as cancer and heart disease, for instance. The statistics generated at this time focused on physical illness and passed over strengths." (Kelm, 1998, p. 3)

More and more Native communities are finding ways to incorporate traditional and Western approaches in patient/client care.

Cultural Values Informed Approach

There are currently 566 acknowledged American Indian/Alaska Native nations in the United States, and more including Native Hawaiian affiliations. These communities have distinct histories, heritage, geography, spiritual beliefs and cultural practices. Although often American, Indian, Alaska Native and Native Hawaiian peoples are grouped underneath a single 'indigenous' or 'Native' umbrella label, each

Native community possesses their own cultural distinctiveness and members within a given community may have very different health beliefs and practices.

In *Colonizing Bodies: Aboriginal Health and Healing in British Columbia 1900-50,* historian Mary-Ellen Kelm (1998) notes the communal nature of health and wellness among Canadian First Nation people. She describes the "monologue" of Western medicine, where healing knowledge is concentrated with a few highly trained individuals, who move from place to place and dispense their duties with no particular attachment to those they give aid to. In a sharp contrast Kelm says indigenous communities spread the responsibility for health more widely - several people held different roles, from herbalists to healers and ceremonial leaders. These ideas of wellness took into account the particular social and spiritual needs of the group. "In Aboriginal cultures, the maintenance of health was everybody's business." (p. 85). And although healers were certainly also highly trained, many times from childhood on, they were also deeply rooted in the location and particular community they lived in.

While many traditional healing ways have passed from memory, others remain, and some values, responsibility and particularly roles in maintaining health persist. As health service providers, volunteers and program staff, we can still call upon these values to guide our work in urban tribal and rural communities.

- Education – learning from all aspects of our lives and from the people we interact with.
- Sharing what we know with others – taking that knowledge and applying it, teaching it and helping others be healthy along with us.
- Respecting all life – knowing all life is interrelated and everyone deserves to be treated with caring and dignity.

Sometimes, there are ways in which our cultures have changed since colonization that affect how we regard each other. Certain ways of being, for instance being gay or two spirit or transgender, may not be readily accepted in some Native communities – even if those communities might have accepted those identities traditionally. This can alienate some clients from needed spiritual and cultural activities, and is troubling given the higher risk of contracting HIV from some of the sexual behaviors associated with those identities. Of course, there are also many communities that welcome and value LGBTQ and two spirit people, despite what colonial social values dictate.

Community Involvement as a Strength

Reconnecting with aspects of our culture can be a means to healing and preventing distress and isolation. Cultural projects such as learning tribal languages, participating in cultural dancing, attending ceremonies, practicing beadwork, refining jewelry-making techniques, participating in shawl making circles and cooking traditional foods can aid in one's overall health and wellness. When we as service providers or PW Counselors can include these opportunities and resources in the buffet of choices for clients, we increase our own cultural understanding, open avenues of healing and increase the chances for client retention in needed care (Ahalaya).

V. Core Competencies and Considerations

As POSITIVE WELLNESS is a structured intervention that is delivered one on one, there is significant onus on the PW Counselor to be able to work efficiently, respectfully, and with intent with a client – some of whom may be presenting with significant issues and concerns. Counselors should be skilled and well-prepared.

Counseling Skills and Techniques

Counselors draw upon myriad skills and techniques that allow them to facilitate discussions, navigate conflicts, elicit participations, manage emotions, and motivate participants to self-explore and ultimately support behavior change. A PW Counselor should be well versed and experienced in working in one on one settings and tapping into the toolbox of skills that will allow them to work with participants. PW Counselors who need development in this area should look at trainings on HIV risk reduction counseling or mentoring with an experienced counselor.

- Open-Ended Questions – using questions that require a narrative response, rather than simple one or two words answers. A PW Counselor should seek to ask more questions that providing their own answers
- Affirmation – providing praise, when appropriate, for participants as they move towards making positive changes in their lives
- Reflecting – restating what you hear the participant saying, especially as it relates to the feelings that are being expressed
- Summarizing – summarizing what you, as a PW Counselor, hear from the participant to help ensure understanding, and bridge to the next topic of conversation
- Nonverbal Communication – body language, eye contact, hand gestures, mannerisms, facial expressions, and physical contact all are strong methods of communication. Counselors should be aware of their own body language and what it conveys, as well as paying attention to the body language of the people they are serving.
- Managing Silence – Western societies teach us that silence is awkward and should be avoided. However, our teachings tell us that silence should be treasured, and used as a time for introspection and reflection. PW Counselors should embrace silence, and not try to avoid it.
- Cultural Considerations – every PW Counselor, especially those that may be non-Native, should seek to understand the local cultural nuances of communication so as to not appear disrespectful (these may include who speaks first, what words are inappropriate to use, the use of eye contact, etc.).

Constructive Feedback

Any behavior change program is going to inherently include attempts at behavior change and exploring how those attempts went. IT is important that a PW Counselor be prepared to offer constructive feedback to the participants. Below are some tips to consider.

- When giving feedback, remember to…
    - Be specific
    - Focus on what the facilitator can change
    - Give an actionable suggestion
- When receiving feedback, remember to…
    - Listen to what the person is saying
    - Ask for clarification if you don't understand a comment or question

Active community-based case management

Community-based case management is a more client-centered approach to delivering case management services. It includes allowing participants to decide upon settings for meetings and sessions that may be more comfortable or accessible to them (i.e., coffee shops, their home, restaurants, parks, or even cars). It also includes scheduling that is more convenient for participants (using varied times to meet the participants' schedules). The active component refers to the consistent efforts on the part of the PW Counselor to identify these needs from the participant and adapt program delivery to meet their needs. Active community-based case management is a sign of respect for the participant.

Extended Counseling

The PW Counselor may also meet with family, friends, or partners, as appropriate and allowed (and facilitated) by the participant to help them understand what HIV is and what changes may be needed to improve health outcomes for the participant. This can help the participant who may not know how to or want to take that role with their family. For many Native people, the support of their family is essential to their well-being. If this is not under the auspice of the PW Counselor to perform, then the Counselor should work with another staff member, CHR, Health Educator or public health nurse to help provide support and education to family, friends or partners.

Substance Use

Substance abuse is an epidemic unto itself in Native communities. Substance use or abuse can keep Native people from accessing the full strength of their communities and cultures. Using substances – including alcohol or tobacco – outside of Native ceremonial or religious settings may be viewed as bad or disrespectful, and known users may not be welcome. Substance users may choose to exclude themselves from traditional practices out of respect, and therefore may lose a connection to traditional healers, medicine and ceremonies. It is also common for newly HIV diagnosed individuals to react with denial, avoidance and fear of disclosure. For many Native people, there may be an added fear of rejection and worry they cannot participate or fulfill a family or traditional role that is important to them or central to their identity. Since substance abuse compounds HIV risk, users and HIV-positive individuals can sometimes be the people who need spiritual healing and balance the most.

The reality for many may be that substance use is a coping strategy for loss, pain, stress, abuse and unfortunately a sense of hopelessness. They may not be healthful ways to cope, but are understandable, and a compassionate, non-judgmental approach is important.

PW Counselors should be aware of substance use locally, and be prepared to not just work with participants who are struggling with addiction, but to help link them to appropriate resources as necessary.

Confidentiality

Maintaining the confidentiality of personal information disclosed by participants in your *POSITIVE WELLNESS* program is absolutely essential. This is especially true in Native communities, where confidentially abuses have occurred, which erode trust in healthcare systems. You and other staff members have the responsibility to ensure that personal information provided to you by participants remains private and is not disclosed to unauthorized individuals or agencies. At the time individuals initially join *POSITIVE WELLNESS*, they are assured the information they provide about themselves, including their name, address, phone number, Tribal affiliation(s), family relations of the participant, sexual orientation and contact person, as well as their drug-use and sexual activities, will remain

confidential (see Participant Session Guide). Participants have a right to expect that confidentiality will be observed by program staff with regard to all information they provide about themselves, even information that we may consider trivial. (See Appendix – Ignacio & Grey, 2013)

HIV-positive individuals who have their status disclosed may be shunned from their family, forced out of their living environment, ostracized from the community, or/and denied participation in traditional and cultural ceremonies. These devastating consequences often drive HIV-positive individuals to keep their status secret from friends, family and health care providers.

Ignacio & Grey, 2013

Concerns over confidentiality have stalled HIV testing and prevention efforts in American Indian, Alaska Native, and Native Hawaiian communities. HIV/AIDS is a socially stigmatized disease in many Native communities, causing a person who is concerned about HIV to feel shame, and often to become isolated from the community or local clinic. Because of close social structures in many Native American communities, clinics and agencies serving American Indians need to be especially careful about confidentiality issues. Breaches occur in small reservation/rural communities, but can also occur in urban clinics. A person's fears about confidentiality may keep him/her from accessing testing, care, treatment, and the *POSITIVE WELLNESS* program. A comprehensive list of strategies to ensure confidentiality is listed in the *POSITIVE WELLNESS Participant Session Guide.*

A foundation of trust and confidentiality facilitates the participant's progress and success in making the transition to living with HIV. It is important to help the participant identify how they want to disclose and to whom. By starting with a conversation about confidentiality and the laws and rules under which the PW Counselor must work, the participant may then feel freer to talk about potential difficulties, fears and possible ways to disclose their status in their own time.

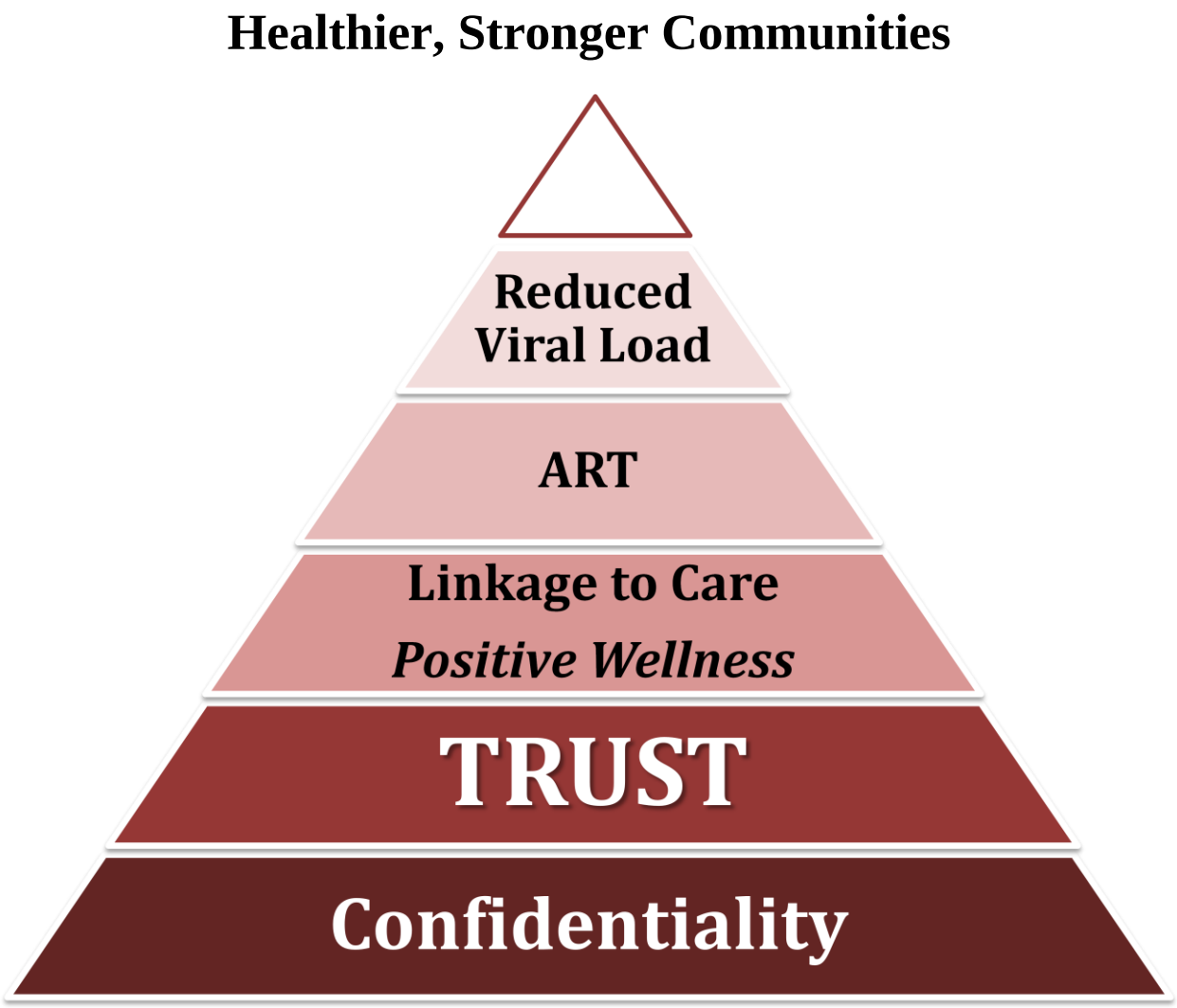
Building Blocks of Healthy, Strong Communities – The Pyramid of Trust

One important reason practicing confidentiality is essential to community health is that it lays the foundation for trust. This is particularly true for HIV, which is a sensitive issue in many communities. It takes not only a single program or organization's commitment, but the concerted effort of all service and

program providers to hold the necessary high standards for confidentiality. Trust makes many things possible, as many of our traditions have shown us throughout history. We've also learned the devastating consequences of mistrust. So now, in the context of HIV, we can see the value of building toward healthier, stronger communities by creating a place of trust for those who are facing a new life with the virus.

When the community, other organizations and potential clients place their trust in you, it increases the ability of your program to link people to needed care. The more people living with HIV who link to medical care, the more who can then benefit from anti-retroviral treatment (ART). Increasing the number of individuals on ART leads to lower individual and community viral loads, which contributes to healthier, stronger communities by reducing the spread of HIV.

Diagram 1: Trust Pyramid



VI. Before You Begin

Underpinning the entire goal of providing effective linkage to care services, is the ability to create strong, respectful and mutual relationships with partner organizations, medical providers, agency staff, the community you serve and the participants. Without trust, communication breaks down and cultural misunderstandings undermine all interactions and activities, no matter how well-meaning the intentions.

- Building trust in the community
- Building trust in partnerships
- Building trust in participants
    - Making sure the participants know what they can expect from you.
    - Reciprocity as a way to establish trust
    - Outwardly expressing respect as a way to establish trust

Know Your Community

Any implementation of *POSITIVE WELLNESS* should always be reexamined through the cultural lens of the community first. Program administrators and PW Counselors should aim to align program activities, language and outcomes with local cultural elements (how disease is talked about, how homosexuality is addressed, concerns about confidentiality, etc.) and the environmental reality (distance to doctor, location of pharmacy, etc.).

Research and experience have shown that the acceptance and effectives of prevention program can be increased in Native communities by including Native images, Native facilitators, Native ways of thinking, and in general creating a Native-friendly atmosphere. With that in mind, a Native adaptation of *POSITIVE WELLNESS* should include risk reduction success stories from Native communities, local or at minimum national Native-specific information and brochures on HIV and Hepatitis C. The meeting space must be welcoming (and not necessarily within the agency), and the social events should be culturally appropriate, resonating with the local community. Inclusion of indigenous language(s) if appropriate for the particular participant groups should be incorporated into the sessions. One example of this would be using indigenous words, cultural stories, symbols and concepts to discuss risk reduction and stages of change.

Community Considerations Checklist

1. Identify Gate Keeper(s) – those individuals or groups that for reason or tradition or structure, controls access to information, decision-making, etc.
2. Size of community directly impacts confidentiality – most rural communities share the challenges of small numbers and tight communication networks about its residents
3. Identify status of Linkage to Care in a community – If one already exists, it is unnecessary to reinvent the wheel, but implementing *PW* may be an opportunity to extend or revitalize existing programs.
4. Familiarize yourself with partner organizations
    - Research potential partner organizations' formal practices:
        - Eligibility criteria
        - Existing MOUs/MOAs with tribal health agencies
        - Hours of operation
        - Key contact personnel
        - Estimated wait times
        - Confidentiality protocols and adherence
    - Informal characteristics:
        - Cultural competency and familiarity
        - Staff and agency's strengths working with participants who have certain needs

    - Personalities of each clinic staff person
    - Understanding of PW Counselor's role and the *PW* model
5. Establish a level of trust between agencies
6. Develop a referral network
7. Keep staff at all levels informed. This is an opportunity to advocate from the frontlines, communicating what you see with participants – their needs, challenges and successes. This can be used to inform organizational decisions on program design, policies and procedures or funding allocations.
8. Develop MOAs or other agreements where possible
9. Working with a culturally connected team approach helps address barriers and challenges of stigma and logistics.
    - Integrate or combine forms to simplify paperwork process
    - AI/AN/NH participants often have co-occurring health issues, team approach helps integrate care in a holistic way
    - Increases the likelihood of continuous support and care, and thus improves adherence to treatment

Referrals

It may not be realistic to assume that a single PW Counselor or even an agency can meet all of the needs of a single person (especially if that person is presenting with multiple healthcare and social needs). Others agencies, providers or organizations may have the resources and expertise to handle what we may not. For this reason, it is important for PW Counselors have a wide and strong referral network at their disposal. We provide referrals for people when their needs do not match up with services we provide, and are not directly relevant to the work you are doing together, but can indirectly derail any progress. When we link to others, we help create a wider circle of care for those who test positive. We can turn to various forms of medical care, social services, individual aide programs for help with needs such as transportation and childcare, and of course, traditional or ceremonial leaders and circles. For *PW*, we are mainly concerned with effective linking to medical care, but best practices in Native communities tell us we must help the person address wider health and wellness concerns by placing medical care in a specific community and cultural context when possible, and by acknowledging the need for holistic balance.

Community Advisory Council

A community advisory council is a wonderful resource to use to make sure that all local implementation efforts are culturally appropriate. Potential advisory council members who are knowledgeable of the community, familiar with HIV and related co-factors, are connected to tribal health and spiritual resources, and are able to review and provide feedback on all developed materials and activities. An active community advisory council can also help to de-stigmatize participation in the program.

However, an advisory council may not be necessary or even feasible for just a single program, but if such a group already exists for the agency as a whole or a related set of programs, it would be potentially advantageous to make them aware of the linkage to care efforts and garner support to fight stigma or bring awareness to the issues around HIV.

Recruiting Native Participants for *POSITIVE WELLNESS*

How you reach out to potential participants will depend in part on how *POSITIVE WELLNESS* is integrated into your program. The most common way for individuals to enter the program is through person-to-person referrals, especially through people who are trusted in the community. These referral sources could be from almost any walk of life, and creating wide ranging networks is a good strategy. Consider the following potential strategies and referral sources:

- Testing programs
- Partnering with testing sites
- Interagency collaboration and partnership
- Marketing materials for *PW* services
- Collaborate with tribal health department
- Seek Capacity Building Assistance (CBA)
- Mentoring, support groups or talking circles
- Referrals from individuals, particularly past *POSITIVE WELLNESS* participants
- Training or presentations with stakeholders or leaders in the community
- Use program or facility name based on cultural meanings, acronyms or other non-HIV specific wording
- Creating or expanding working relationships with ceremonial and traditional leaders
- HIV-positive role models (who may come from outside the local community)

Literacy Levels

Promoting or recruiting efforts for *POSITIVE WELLNESS* may include written materials, flyers or participant forms. Care should be taken to include people of different comfort levels with reading and writing the English language. Some materials may need to be produced in the local Native language(s). Reviewing these materials is one important way a peer or community advisory council can engage in the program. PW Counselors should not assume all participants can read or write. It may also be useful to allow for time to read program written materials to the participants as well.

Note: A Pre-Implementation Worksheet is included in the Appendices to aid with preparing to implement *POSITIVE WELLNESS* in your agency or organization. This worksheet will help you identify potential challenges or barriers to implementation, steps to take toward addressing those barriers and specifying who will take the lead in taking those steps.

Guidance is a Cornerstone to help us fulfill our purpose and our Vision.

Remember, no matter how sad we are, how hopeless we feel, or how deep in the darkness we find ourselves to be – our Ancestors left us their light and wisdom to follow.

Their voices live within us, their values are reflected in our actions, and it is our responsibility to share our strength with those who seek these ways.

The hope that our Ancestors left us is found within our own heart's desire to grow and change, and the belief that we can achieve our Visions of living a life of health, wellness and balance.

Somehow we may find ourselves in a difficult situation, or in the midst of a painful relationship, but we need to remember our elders and Ancestors experienced these same feelings and somehow survived.

This is why it is important to honor our elders today. Somehow they survived experiences we cannot imagine and drew strength to move forward.

Remember the Light of Hope Left Us by Our Ancestors.

- Tom Lidot, *Tlingit*
From *Creating a Vision for Living with HIV in the Circle of Life*

V. Monitoring and Evaluation of *POSITIVE WELLNESS*

Potential benefits of M & E

It is frequently noted Native-specific data, particularly around HIV and AIDS, is sparse, inaccurate and/or incomplete. In 2012 the CDC released a publication - Report; improving HIV surveillance among American Indians and Alaska Natives in the United States - based on research and input from the AI/AN community on how they and other health agencies can improve data gathering and address the goals of HIP and the NHAS. In the report they note the lack of data, and data gathered in culturally insenstivie ways, can have negative impacts on health for those communities. The CDC gives several recommendations on ways to improve data gathering, including working with tribal governments and health agencies to be more culturally accurate, and indentify data needs and challenges.

Gathering your own data can help in many ways, especially when the data can be used to improve and expand local health care efforts and goals within the community. Data can be quantitative, such as numbers of program participants, number of participants who self-report their satisfaction with the program, or any of the items on the *POSITIVE WELLNESS* Sample Evaluation Sheet detailed below. Data can also be qualitative, and with the proper confidentiality measures in place, be gathered from Participant Session Summaries. It is during sessions that Counselors may identify consistent patterns, challenges, best strategies and practices and inform organizational policy making and program planning.

Data can benefit programs locally and regionally by providing accountability to funders, participants and organization staff. It can inform program improvement by identifying goals, successes, challenges and feedback from stakeholders.

Evaluation Plan for POSITIVE WELLNESS Program (see Appendices)

An evaluation plan is an important part of any program implementation, especially one that runs over a period of time or involves multiple parties – clients, counselors, support staff, testing sources, medical providers and/or partner organizations. The purpose of an evaluation plan is to create a system of tracking and monitoring that helps ensure the program is operating effectively and meeting its goals. An evaluation plan can encourage staff to improve their work with clients to achieve self-identified goals. It can also provide data that can then be reported back to program administrators, tribal councils, community stakeholders and funders. Data gathered in evaluation can also inform future grant applications, and program and service development and planning.

Evaluation plans should include a mixture of the following data:

- Process Monitoring Data: data describing how the services are delivered and to whom
- Process Evaluation Data: data that describes how successful the program has been at achieving stated objectives
- Outcome Monitoring Data: what has happened or what changes occurred as a result of program implementation (i.e., behavioral changes in clients)
    - Short-term or Immediate: outcomes reported immediately on completion of the project (e.g., increased self-efficacy to talk about HIV with a doctor, increased knowledge of how to schedule an appointment, increased knowledge of how HIV affects the body)
    - Longer-term or Intermediate: What happens after a client begins to apply what they learn (e.g., scheduling 2nd or 3rd appointments with a medical provider, maintaining scheduled doctor's appointments, beginning ART)

An evaluation plan does not have to be overly complicated, but should include the following elements:

- Goal: A general statement of what you hope to achieve with your program or services.

- Objective: A more detailed statement (in the SMART format) that will bring you closer to achieving one component of your goal. There can be multiple objectives for a single goal.
- Performance Indicators: A descriptive statement of how you know you are being successful in your program – usually through increasing positive outcomes or decreasing negative outcomes through the program. This shows your success and if your program is doing what it set out to do. There can be multiple performance indicators for a single objective.
- Performance Measures: What you need to measure or the data you need to collect in order to be able to report on your performance indicator. There can be multiple measures for a single performance indicator. Measures can be qualitative or quantitative.
- Data Sources: What methods will be used to capture the data described in your measures. Some examples are Intake Forms, Client Referral Forms, Attendance Sign-in Sheets, Evaluation Forms, etc. Sometimes the exact data sources are not known at the time of creating the evaluation plan for particular activities, and can be reported as 'to be determined'.
- Data Collection Plan: A detailed description of who will collected what forms of data and how.
- Data Analysis Plan: A detailed description of any methods or software that will be used to analysis data.
- Data Management Plan: A detailed description of how the data will be stored both in the short term and long term.

An evaluation plan may also include some of the following additional elements:

- Benchmarks: Time-based goals to be achieved at certain intervals throughout program implementation. These are generally process oriented (especially around number of people enrolled at a certain time, or number of people completing the complete program at a certain point in the grant cycle).
- Parties Responsible: Should a project team or clinical staff already be in place, then responsibilities for various parts of the evaluation process can be assigned to certain people as part of the evaluation plan.

Data Collection Considerations

- Who will be responsible for collecting data and tracking information
- What data system will the program use to collect electronic information?
- How much of the data will be self reported?
- Will the client, the counselor or a combination complete forms?
- Where and in what forms will the data be collected (and what new forms will the program/clinic/organization need to create)?

Data Analysis Considerations

- Who will conduct the data analysis?
- What data system or software programs will the program use to produce reports?
- What types of analysis will be used to interpret data?

Data Management Plan Considerations

- Where will the data be stored?
- How secure is our data storage system?
- Will paper records, electronic records or a combination be used to data storage and tracking?
- How long will data and forms be stored before they are disposed of?
- How will we dispose of old data and forms?
- Are the electronic data stored on a secure server?

Appendix D is a sample evaluation plan for *POSITIVE WELLNESS*. This can be used as a template for any organization seeking to implement *PW*, although adaptations would need to be made to reflect local variances in objectives (especially target numbers), appropriate timeframes and systems that may already be in place to collect participant-specific data. This template is a skeleton and only reflects the minimal data elements to be collected on a *PW* program. Organizations/tribes/clinics should explore what additional elements they have the capacity to collect and report on in order to strengthen their own internal program evaluation.

Creating SMART objectives

SMART objectives refers to a specific framework for writing your program objectives so they are directly connected to project activities, clearly and are able to be evaluated. SMART is an acronym that actually stands for Specific, Measurable, Achievable, Realistic and Time-based.

Specific – Does the objective clearly specify what will be accomplished and by how much?

Measurable – Is the objective measurable?

Achievable – Is this objective reasonably attainable?

Realistic – Does the objective make sense with program goals, and mission of the program?

Time based – Does the objective specify when it will be achieved?

There are two basic types of objectives:

- **Process objectives** state what and how you will be doing the program activities and in what timeframe they will be completed.
  - EXAMPLE: Complete a culturally appropriate strengths self-assessment with all PW participants during the course of session participation
- **Outcome objective**s state specific immediate and intermediate results of the program. These outcomes are usually measured in more than one way, and depending on scope of the outcome, may not have a specific timeframe beyond, "after participating in the program."
  - EXAMPLE: Increase the number of HIV-diagnosed participants who attend at least one medical appointment for HIV care within 6 months of beginning the PW program.

Special note: This process of forming objectives for a program can be used for personal goal setting for the participant as well.

Indicators of Success

Indicators describe program progress and successes. Examples of indicators might be increases in attendance, increase in participant retention rate, decrease in drop-out rate or increase in number of participants linking to care.

Measures are the information we collect to demonstrate the indicator. For example, we would collect data on how many people attended an outreach testing event. We could then compare one event to another over the course of a year to see if we increased attendance. If we did, this would be an indicator of success. Another example would be to keep track of how many new participants we have in a year, and compare that to other years the program has been implemented. One indicator of success would be an increase. We include these numbers, and the goals for those numbers we hope to make in a specific amount of time.

Preparing for Evaluation

Evaluation capacity – the ability to conduct an effective evaluation and use the findings for program improvement
Questions to ask before evaluation:

1. Is there a willingness to evaluate?
2. Have the intended users of the evaluation been identified?
3. Is there a logic model describing planned implementation and outcomes?
4. Have evaluation questions been identified?
5. Is there a desire to use the evaluation findings?
6. Have data needs been determined?
7. Are the data needed available or feasible to collect?
8. Have evaluation resources been secured?
9. Have data collection, management and analysis procedures been developed?
10. Is there a strategy to distribute and use the evaluation findings?

Using Evaluation Data

The saying goes, "Don't ask unless you want the answer." This is true for many questions in life, including the questions we ask in gathering data. The flip side of that saying is to use the data you gather. If it sits in a file cabinet or on a server somewhere, it cannot benefit your agency or your community. Sometimes, agencies and organizations do not understand the value of good data handled well, and some education and persuasion may be necessary. Strategies to promote using evaluation data:

- Develop buy-in among evaluation stakeholders
- Clearly identify the intended users of the data
- Identify evaluation questions meaningful to the intended users
- Decide how the data will be used before the evaluation is conducted
- Present data in a user-friendly format

There are many other strategies and uses for data that can help improve services and interactions with potential and current clients. Keep an open mind toward using data to help promote and grow your services and programs.

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Additional Related Research

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