Welcome

CHANGE is crucial to growth. In response to current developments and the shifts occurring in the HIV/AIDS field, the *Navigating Changing Environments: A Leadership Toolkit* has been created by the Latino Commission on AIDS for use by community organizers, advocates, healthcare providers, community-based organizations, faith-based organizations, and others. The toolkit is organized along the **LUKA Principle**, with an additional section highlighting evaluation.

The **LUKA** (Leadership, Unity, Knowledge, Action) **Principle** is a unique model for leadership development that takes into account the need to support and build local leadership, unite communities, enhance knowledge, and to take action. In the following videos you will be introduced to each of the components of the **LUKA Principle** to give you the necessary framework you need to navigate this toolkit effectively.
Each section of the toolkit includes an introduction to how the principle relates to mobilization efforts to navigate the changing landscape; tools; and case studies illustrating the principle in practice. To maximize the usefulness of the toolkit, the tools and case studies come from a variety of sources both in the HIV/AIDS field and pertaining to other types of organizing for change.

“Navigating changing environments” is inherently an evolving process and requires a changing set of skills and resources. The Latino Commission on AIDS looks forward to your feedback as a user of this toolkit, with a view toward making it truly a living document. We encourage and welcome you to use the following email link or leave a comment in the available section at the bottom of each page.

For ease and usability, the toolkit is downloadable and printable. You may use the menu buttons at the bottom of each page to export the toolkit into the social and digital medium you most see fit. In order to get the best product when printing the toolkit we recommend printing in “portrait” mode.
The **LUKA Principle** brings into focus important elements that have been identified by stakeholders as necessary in building a cohesive front to undertake the issue of health disparities. Within the United States, health disparities are often the result of multiple overlapping issues (not just individual beliefs or actions). Race or ethnicity, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual’s ability to achieve good health.

The model grew out of the *Commission’s* experiences building the capacity of organizations in states that serve an emerging Latino community, as well as engaging community members to lead community mobilization efforts in their areas. It recognizes the importance of local, grassroots leadership in uniting communities and forming effective coalitions dedicated to improving living conditions and to addressing the HIV/AIDS epidemic and changing policy environment. The model also focuses on the need to systematically collect data to enhance and continuously update leaders’ and coalitions’ knowledge of the community, in order to inform actions. As such, the **LUKA Principle** is an iterative process of gathering information, engaging leaders, and taking actions to advocate for services and policies in working to reduce the impact of HIV/AIDS on the community.

*Figure 1 below presents a visual representation of the model. Leaders build upon the initial identified needs, to bring together a coalition in Unity, this unified group then engage in a community assessment to gather in-depth Knowledge. The actors involved then formulate Actions based on the information. Once that process is complete, the coalition reassesses any changes that have occurred, within the social, political, and economic contexts that affect the*
population. Following the reassessment, the iterative process begins again, to once more plan actions that, if successful, impact the community’s living conditions. As shown in Figure 1, evaluation is a key part of each step of the process, with feedback loops established to help the organizers understand whether the action steps are proceeding as planned, and opportunities to assess progress along the way.

**The LUKA Principles**

A key part of implementation of the **LUKA Principle** is an assessment of the community’s readiness for mobilization. That readiness depends on:

- The community’s history with mobilization efforts, including actors involved, successes/struggles, lessons learned, barriers encountered.
- The key players in the community, and whether those have changed over the years.
- The key issues of concern to the community at the moment.
- Opportunities to effect change.

The Commission has identified eight core elements of implementing the LUKA Principle:

1. Defining who is the emerging population
2. Leadership assessment and development
3. Resource mapping
4. Stigma mapping
5. Leveraging resources
6. Understanding and addressing the individual, organizational and environmental barriers to accessing care
7. Understanding and addressing health disparities
8. Evaluation

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The Toolkit at a Glance

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Toolkit Sections

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The Navigating Changing Environments: A Leadership Toolkit is organized along the LUKA Principle, with an additional section highlighting Evaluation. Each section includes an introduction to how the respective principle (Leadership, Unity, Knowledge, Action) relates to development of community mobilization efforts to impact the HIV epidemic and changing policy landscape; tools; and case studies illustrating the principle in practice. To maximize the usefulness of the toolkit, the tools and case studies come from a variety of sources both in the HIV/AIDS field and pertaining to other types of organizing. Take a few minutes to review what we have discussed so far so you are better able to utilize the tools presented here. Use the links below as an overview of the tools and case studies, you will also find them as you go through each section.
Section Overview: Leadership – Unity – Knowledge – Action – Evaluation

Leadership

- Individual Level
- Organizational Level
- Community Level

Unity

- Goals
- Shared purpose
- Values

Knowledge

- Steps in Community Assessment

- Investigation into existing data sets
- Definition of target population
- Survey of internal/external staff
- Community observation
- Community mapping
- Focus groups

- Spot interviews
- Gatekeeper interviews

Action

- 1. Organize the community for action
- 2. Explore the health issue and identify priorities
- 3. Plan together
- 4. Act together
- 5. Evaluate together
- 6. Prepare to scale up

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- 1. Sister Love: “Reflection on Social Justice Organizing and Leadership”
- 2. The Beloved Community: “Building Black-Brown Coalitions in the Southeast”

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- 2. Community Observation: Safety Tips
- 3. Sample Data Collection Tool for Community Observation
- 4. Community Observation Tool: Stigma and Values-Indicators
- 5. How to Conduct Key Informant Interviews
- 6. Child Needs Assessment Tool Kit
- 8. Focus Group Guide
- 9. Community Health Needs Assessment Guidelines
- 10. “Concentrated Rural Poverty and the Geography of Exclusion”
- 11. What is Policy? Fact Sheet
• 12. Racial Equity Impact Assessments
• 13. Hispanics/Latinos and HIV/AIDS Fact Sheet
• 14. Risk Factors and Recommendations: HIV/AIDS and Rural Hispanic Immigrant Women
• 15. Rural Hispanic Immigrant’s Perspectives on HIV/AIDS
• 16. “The Undercurrents Impending HIV Prevention/Testing Among Rural Hispanic Immigrants”

Case Studies

• 1. “Growing from Groundwork: Stories and Tools from the Reproductive Movement”
• 2. Southern Echo
• 3. “Our People are Still Resisting”: Farm Worker Community Organizing and the Texas Agricultural System

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• 3. Austin Roundtable Guide: Proposed Plan, Format and Instructions
• 4. Evaluating Community Collaborations
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Case Studies

• 1. The North Carolina Harm Reduction Coalition (NCHRC) Organizes North Carolina Advocates to Participate in the National Day of Action on Syringe Exchange
• 2. The North Carolina Harm Reduction Coalition (NCHRC) Law Enforcement Safety Training Program

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• 1. Coalition Member Assessment
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Case Studies

• 1. Promoting Healthy Public Policy through Community-Based Participatory Research: Ten Case Studies
• 2. Realidad Latina: Latino adolescents, their school, and a university use Photo Voice to examine and address the influence of immigration
Complex issues such as health disparities, HIV and other highly stigmatized conditions or characteristics require leadership from all backgrounds, experiences and perspectives. As a result, the **Leadership** module is culturally appropriate and speaks directly to these diverse leaders.
Whether you are an emerging or established leader, understanding your style, strengths and areas for growth are key for remaining an effective and relevant leader. This section includes the following tools to help you assess your own leadership style:

**Leadership-TOOLS:**

1. **The Leadership Style Assessment**, to explore leadership along a series of dimensions.

2. **The Personal Style Inventory**, worksheet to determine your personality signature.

3. **The 360-Degree Feedback Tool**, is meant to be completed by one’s supervisor, one’s colleague, and someone who reports to the person being evaluated.

4. **The Conflict Management Styles**, worksheet guides you through a detailed assessment of the types of conflict management you use in a variety of situations.

**Leadership-CASE STUDIES:**

We have also compiled case studies to illustrate lessons learned about building leadership.

1. **Never Say “Help”**, includes lessons from leaders from diverse geographic and organizational contexts.

2. **“Perceptions of Leadership and Policy Issues in the Latino Communities of the Deep South”**, an assessment report conducted by the Latinos in the Deep South program at the Latino Commission on AIDS.

3. **“ACT UP Explained”** a moving narrative describing how assuming a position of leadership was a way to overcome individual fears associated with HIV/AIDS.

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People are stronger together than apart! Hence it is extremely important as a leader to focus on building networks. In the case of our organization, this has resulted in the development of several regional and state coalitions and work groups. These networks have conducted activities specifically for National Latino AIDS Awareness Day, as well as identified assessment needs and met with non-traditional partners such as faith-based organizations, elected officials, nursing schools, academic researchers, harm reduction programs, policy groups, health departments and law enforcement.
Unity-TOOLS:

1. Planning for Change – Coalition Building the Basics, reviews the certain coalition building basics.

2. The Ohio Community Collaboration Model, This model relies heavily on community partnerships.

3. Resource Mapping Tool, focuses on the process of identifying partners for an effective coalition and assessing what they bring to the table.

4. Mobilizing the Community, goes over multiple issues and concerns when mobilizing a community.

5. Coalition Building Tool – Organization Fact Sheet, guides the reader through a series of questions to document the nature of a coalition to help explain it to potential new members.

6. Community Organizing, makes the case for the power of collective action

7. Turf Issues, explores how turf issues arise among coalitions and what can be done to resolve and avoid turf battles.

8. The Coalition Volunteer Job Description, presents an example of a position description, with the purpose of clearly delineating coalition member roles and responsibilities.

Unity-CASE STUDIES:

We have also compiled case studies to illustrate lessons learned about building Unity.

1. Sister Love, Sister Love’s organizing strategy is straightforward, and it begins with personal transformation: the organization believes that people have to accept themselves before they can engage in public policy matters.

2. The Beloved Community, focuses on the work of people affiliated with The Beloved Community Center of Greensboro.
A key to building Knowledge is to understand where all the program partners are at, in terms of local values, beliefs, skill sets and goals. Here community partners, stakeholders and policy assessment are key. Keeping regular contact with program partners, and involving them in as many training opportunities as possible is key to success. This should result in enhanced skills on community mapping, cultural competence, AIDS stigma, and advocacy. An example of this is how through its community organizing branch, Latinos in the Deep South has pushed for change on specific policy issues like syringe access and the National HIV/AIDS Strategy.
**Knowledge-TOOLS:** For ease of use we have grouped the following tools in three categories: [Methodology Tools](#), [Data Collection Tools](#) & [Background Information Tools](#)

**Methodology Tools**
1. **MSMGF Research Topics**, to help determine which Research Topics are relevant for the local MSM community.

2. **Child Needs Assessment**, guides the user through survey methodology, and how to plan a community survey.

3. **Community Health Assessment**, walks the reader through the process of assessing health status and healthcare needs in the community.

4. **Racial Equity Impact Assessment**, presents the methodology of conducting impact assessments and examples.

**Data Collection Tools**
5. **The Community Observation Tool**, includes safety tips and what to document while conducting observations in the community.

6. **Data Collection Grids**, provide a way to organize and document community observations and spot interviews by listing key variables.

7. **Stigma Mapping Tool**, provides a way to note stigma indicators observed in the community.

8. **Key Informant Interviews Tool**, provides an overview of what to look for in a key informant and how to schedule the interview, along with a sample interview guide.

9. **NLAAD Street Intercept Survey**, survey that was used to assess community members’ awareness of National Latino AIDS Awareness Day.

10. **Focus Group Guide**, to assess HIV testing and prevention knowledge.

**Background Information Tools**
11. **Concentrated Rural Poverty and The Geography of Exclusion**, details the challenges of measuring rural poverty and presents nationwide data.
12. *What is Policy?* Fact Sheet, summarizes potential policy tools at an organizer's disposal.


14. *HIV-AIDS and Hispanic Women-Latinas*, presents HIV incidence and prevalence information specific to women, along with risk factors.

15. *Recommendations HIV-AIDS and Rural Hispanic Immigrant Women*, contextualizes HIV risk factors particular to this population of Latinas in the South.

16. *Rural Hispanic Immigrant Perspectives on HIV-AIDS*, presents the findings of the organization’s 2010 Community Survey that informed approaches to local HIV prevention campaigns in the South.

17. *HIV Prevention-Testing among Rural Hispanic Immigrants*, reviews the data connecting the lack of accurate HIV/AIDS incidence data for Latinos in the South with social determinants of health and the anti-immigrant political climate.

**Knowledge-CASE STUDIES:**

We have also compiled case studies to illustrate lessons learned about gathering Knowledge.


2. *Southern Echo*, a case study of community development and relationship building among diverse communities in Mississippi.

3. “*Our People are Still Resisting*: Farm worker Community Organizing and the Texas Agricultural System,” explains the process of farm workers’ community organizing.
Without Action, developing Leadership, Unity and Knowledge remains untapped. Hence the **Action** module is rooted in the previous principles – **Leadership**, **Unity** and **Knowledge**.

This section includes the following tools to help you and your community jump into action:
Action-TOOLS:

1. Action Planning Worksheet, is one way to organize your ideas about your initiative and clearly lay out what is needed to achieve the proposed objectives.

2. Tools for Planning and Implementing a Successful HIV and AIDS Treatment Advocacy Campaign, this information toolkit includes practical ways to understand, plan and start advocacy work on HIV related treatment.

3. Austin Round Table Guide: Proposed Plan, Format and Instructions, a template for running an action planning roundtable group, first used at a community forum.

4. Evaluating Community Collaborations, provides tools for tracking responsibilities during action planning and implementation.

5. Organizing a Community Forum, prepares the user to gather the resources and plan a community forum event.

6. Public Participation Toolbox, reviews a large variety of approaches to public participation.

7. Partnership Tools, presents three examples of checklists to track action planning partnerships.

8. Grassroots Advocacy 101. Making your voice heard in Congress and in the White House, this is a basic guide to advocacy channels in the U.S. Congress.

9. How to work with Elected Officials, provides basic tips for community advocates to build relationships with elected officials.

10. Sample Letter to Elected official raising a concern, may be adapted to the issue you would like to share and for which you would like to gain support.

11. How to Testify at a Public Hearing- Sample Testimony, offers a sample of how to effectively present testimony at a public hearing concerning a health issue.

12. Types of Civic Engagement & Action, is a list of types of engagement in the community.
13. Sample Letter to Stakeholder-MS Division of Medicaid, this letter was created by a group of advocates while attending the 2012 Mississippi State AIDS Conference.

14. Social Marketing Plan, guides the reader through the main points of launching a social marketing campaign.

15. Working with the Media: Nonprofit Toolkit, a comprehensive review of techniques to improve your organization’s media relations.

16. Lay-Health Worker Outreach, presents a summary of the lay health worker (or promotora) approach from the Voices of Immigrants in Action.

17. Women’s Health Literacy, reviews health literacy as a capacity central to engaging in health encounters and the importance of developing this skill among immigrant Latinas.

Action-CASE STUDIES:

We have also compiled a few case studies to illustrate some lessons learned about getting into Action.

1. The North Carolina Harm Reduction Coalition (NCHRC) Organizes North Carolina Advocates to Participate in the National Day of Action on Syringe Exchange., on March 21st NCHRC organized three actions: a mass letter writing campaign, a phone bank and a meeting with Senator Hagan’s office in Raleigh, NC.

2. The North Carolina Harm Reduction Coalition (NCHRC) Law Enforcement Safety Training Program., the relationship between law enforcement and drug users is not always positive, but fortunately, that doesn’t have to be the case.

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The success of community organizing and programs can only be determined after the activities are appropriately assessed and evaluated. Monitoring and evaluation are crucial activities to determine if an initiative is producing the desired results, and if the results are equally valuable to the community, Community-Based Organizations (CBOs), coalitions, and other stakeholders such as funders.

This section includes the following tools to help with your evaluation process:
Evaluation-TOOLS:

For ease of use we have grouped the following tools in two categories: How To Tools & Data Collection Tools

How To Tools

2. **Community Development Evaluation Story Map**, community based organizations, funders, and intermediary organizations working in the community development field have a shared interest in building stronger organizations and stronger communities. This project is a response to those concerns.

3. **Social Marketing Evaluation: How you know whether or not you’ve “moved the needle”?**, a tool that will help you organize your social marketing campaign evaluation plan.

4. **Strategies to Overcome Evaluation Barriers**, a tool that reviews some of the barriers and offers solutions to overcome them.

5. **Tips for a Successful Evaluation**, a summary of tips and strategies for making sure that the evaluation is a success.

Data Collection Tools
6. **Coalition Member Assessment**, adapted from earlier satisfaction surveys by Gillian Kaye and Steve Fawcett.

7. **Evaluating Community Collaborations**, a practical approach to evaluating coalitions.

8. **Evaluating a Community Forum**, a survey to assess participants’ experiences at a community forum.

9. **Legislative Visits Tracking Form**, a way to document the success of visits to legislators to advocate for policy change.

11. Additional Resources, four additional sources of tools and information for developing evaluation strategies.

**Evaluation-CASE STUDIES:**

We have also compiled case studies to illustrate lessons learned about evaluating you or your coalition’s actions.

1. Promoting Healthy Public Policy through Community-Based Participatory Research: Ten Case Studies, list of case studies of diverse community-based participatory research.

2. Realidad Latina: Latino adolescents, their school, and a university use photovoice to examine and address the influence of immigration, a photograph exhibition and community forum raised awareness among local decision-makers and community members of the issues and assets of Latino adolescents and initiated a process toward change.

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A thru D

**AIDS Service Organization (ASO):** A health association, support agency, or other service actively involved in the prevention and treatment of HIV/AIDS.

**Capacity:** often refers to skills, knowledge and ability but can also include things such as access, leadership, infrastructure, time, commitment and resources and all that is brought to bear on a process to make it successful (Frank & Smith, 1999).

**CD4 count:** A measurement of the number of CD4 cells in a sample of blood. The CD4 count is one of the most useful indicators of the health of the immune system and the progression of HIV/AIDS. A CD4 cell count is used by health care providers to determine when to begin, interrupt, or halt anti-HIV therapy; when to give preventive treatment for opportunistic infections; and to measure response to treatment. A normal CD4 cell count is between 500 and 1,400 cells/mm3 of blood, but an individual’s CD4 count can vary. In HIV-infected individuals, a CD4 count at or below 200 cells/mm3 is considered an AIDS-defining condition.

**Centers for Disease Control and Prevention (CDC):** An agency of the U.S. Department of Health and Human Services (HHS) that is charged with protecting the health and safety of citizens at home and abroad. The CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion
and education activities designed to improve the health of the people of the United States.

**Clinical Trial:** A research study that uses human volunteers to answer specific health questions. Carefully conducted clinical trials are regarded as the fastest and safest way to find effective treatments for diseases and conditions as well as other ways to improve health. Interventional trials use controlled conditions to determine whether experimental treatments or new ways of using known treatments are safe and effective. Observational trials gather information about health issues from groups of people in their natural settings. Clinical trials may be prospective (studying data from a time point forward) or retrospective (studying data from collected records in the past).

**Community:** A fluid concept in that it has various dimensions, means different things to different people and the boundaries and membership are constantly. While community is often viewed as an ideal and harmonious unit, it must also be seen as diverse and characterized by degrees of difference and naturally occurring conflict. Definitions of community can be categorized according to sociological, systems, and individual perspectives. Communities may be geographic, non-geographic, the general public, and users of service (compiled from Calgary Health Region, 2002; Centers for Disease Control and Prevention, 1997; Social Planning Council of Winnipeg, 2000; Winnipeg Regional Health Authority, 2007).

**Community Based Organization (CBO):** A service organization that provides social services to local clients. CBOs include nonprofit organizations and free clinics targeted at helping people with HIV.

**Community-Based Participatory Research (CBPR):** A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities. (cdc.gov)

**Community Building:** Organizing a group of people around a shared goal, and then getting them to work together in ways that will achieve it (Lenihan, D., Barber, T., Fox, G. & Miljoy, J., 2007).
Community Capacity Building: Development work that strengthens the ability of community organizations and groups to build their structures, systems, people and skills so that they are better able to define and achieve their objectives and engage in consultation and planning, manage community projects and take part in partnerships and community enterprises. It includes aspects of training, organizational and personal development and resource building. It places the emphasis on existing strengths and abilities, and is based on an assumption that communities which have an active and spirited citizenry will be robust, vibrant, more caring and have fewer social problems (compiled from Frank & Smith, 1999; Murphy & Thomas, 2005; Winnipeg Regional Health Authority, 2007).

Community Engagement: A process of involving, at various levels of participation, empowerment and capacity, groups of citizens affiliated by geographic proximity and/or special interest and/or similar situations to address issues affecting the well being of those citizens. The process is based on interpersonal communication, respect and trust, and a common understanding and purpose. It strengthens the capacity of communities to take action that produces positive and sustainable changes locally, promotes and facilitates community participation in the formation of policy and delivery of services, and fosters collaboration across government departments and throughout the community in relation to issues affecting quality of life (adapted from Centers for Disease Control and Prevention, 1995; Department of Emergency Services, 2001; Home Office, 2005).

Community Level Intervention: Community-level interventions are a promising approach for preventing the spread of HIV infection (Kelly, 1999). Community-level interventions typically combine the use of mass media messages (e.g., through TV or radio PSAs) and/or “small media” materials (e.g., flyers, newsletters) with outreach by program staff or peer volunteers. These individuals engage community members in discussion about HIV and call attention to or reinforce the prevention messages in the media (McAlister, 1991).

Community Mobilization: An attempt to bring both human and non-human resources together to undertake developmental activities in order to achieve sustainable development.
**Community Participation:** A term often used synonymously with involvement. People are supported to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve a change.

**Consultation:** A level of engagement where the objective is to actively seek and obtain a community response (views and opinions), before a decision is made, on possible solutions related to policies, programs, services, or issues. Communities’ views are one of a variety of sources of input that are taken into consideration in the final decision made by the organization (adapted from Vancouver Coastal Health, 2003; Winnipeg Regional Health Authority, 2007).

**Controlled Trial:** A control is a standard against which experimental treatments may be compared and evaluated for safety and effectiveness. In clinical trials, one group of patients may be given an experimental drug, while another group (the control group) is given either a standard treatment for the disease or a placebo.

**Cultural Competence:** Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. ‘Culture’ refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. ‘Competence’ implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities. (Adapted from Cross, 1989).

**Cultural Responsiveness:** Cultural responsiveness describes the capacity to respond to the healthcare issues of diverse communities.

**Empowerment:** A process whereby individuals or communities gain confidence, self-esteem and power to articulate their concerns and ensure that action is taken to address them.
**Ethnicity and Race:** Consideration of race and ethnicity as risk factors rather than risk markers may compromise scientific rigor. For example, race and ethnicity data are often used epidemiologically to explain all variation between groups that remains after controlling for age and gender. Because data on socioeconomic status and income are not available, associations between race or ethnicity and health outcomes may not be further examined for confounding. Use of race and ethnicity data in surveillance may reinforce stereotyping, mistrust, and racism. The use of race and ethnicity data in public health surveillance may foster stereotyping and stigmatization. The collection of data on race and ethnicity may evoke mistrust of data gatherers by persons and groups about whom public health surveillance data are gathered. The use of race and ethnicity data fosters an inappropriate ‘minority model’ of public health and health care, suggesting that affected subpopulations are ‘high risk,’ ‘hard to reach,’ ‘hard to serve,’ or ‘noncompliant.’

**General Public / Public:** The general group of individuals/citizens who, though interested in social services, do not choose to have the same level of involvement in decision-making as service users or consumers, their families, advocates, etc. (adapted from Vancouver Coastal Health, 2003).

**Health Disparity:** Differences in health status among distinct segments of the population including differences that occur by gender, race or ethnicity, education or income, disability, and geographic location. (North Carolina Health Objectives, 2010).

**Health equity:** Equity in health is the absence of systematic disparities in health (or in the major social determinants of health) between groups with different levels of underlying social advantage/disadvantage—that is, wealth, power, or prestige. Assessing health equity requires comparing health and its social determinants between more and less advantaged social groups. These comparisons are essential to assess whether national and international policies are leading toward or away from greater social justice in health.

**Hispanic:** Of or relating to Spain or to Spanish-speaking countries, esp. those of Latin America. (Wikipedia)
**Incidence:** The rate of occurrence of new cases of a particular disease in a given population, often reported as the number of cases per 100,000 people.

**Integrated Service Delivery:** Integrated Service Delivery is about serving Manitobans better. It is a Department initiative to transform policy development and service delivery towards a more accessible, seamless and responsive service delivery system in support of individuals, children and families (Manitoba Family Services and Housing, 2004).

**Intersectoral Networking:** Forming and building relationships between different jurisdictions or sectors in order to take action on an issue or achieve outcomes in a way that is more effective, efficient or sustainable than could be achieved by one jurisdiction or sector working alone. Actions taken and outcomes achieved support the health and well-being of individuals, communities and populations by addressing the determinants of health.

**Involvement:** A term often used synonymously with participation. It implies being included as a necessary part of something.

**Latino/a:** A Latin American inhabitant of the United States. (Wikipedia)

**Local Area Development:** Involves the development of community capacity and citizen involvement in building healthy communities i.e., enabling and supporting citizens in coming together to address issues that impact the health of a community.

**MSM:** An abbreviation for the term men who have sex with men.

**National Institutes of Health (NIH):** A multi-institute agency of the U.S. Department of Health and Human Services (HHS). NIH conducts research in its own laboratories and funds research in universities, medical schools, hospitals, and other research institutions throughout the United States and abroad.

**Organizational Capacity Building:** The work that strengthens and enables an organization to build its structures, systems, people and skills so that it is better able to define and achieve objectives while engaging in consultation and planning with the
community, and taking part in partnerships. It includes aspects of training, organizational development and resource building.

**Prevalence:** The number of people in a population who are affected with a particular disease or condition at a given time. Prevalence can be thought of as a snapshot of all existing cases of a disease or condition at a specified time.

**Prevention Program:** A system of services, opportunities, or projects, designed to stop something from happening.

**Pre-Exposure Prophylaxis (PREP):** The use of antiretroviral drugs as a preventive measure to potentially decrease the risk of HIV transmission.

**Public Participation:** The process by which public concerns, needs and values are incorporated into governmental decision making. Public participation involves two-way communication with the overall goal of better decisions, supported by the public. Participation processes may be single event or they may be embedded in long-term system activities or partnership processes.

**Stakeholders:** Persons who have a personal stake in the issue at that time. Stakeholders include but are not limited to providers, clients, organizations, communities, expert advisors, other government departments, and politicians. They also include partners who collaborate to reach a mutually accepted goal.

**Standard Of Care:** A treatment plan that experts agree is appropriate, accepted, and widely used for a given disease or condition.

**Statistically significant:** When a result of a statistical manipulation is unlikely to have occurred by chance.

**Structural level intervention:** Structural interventions locate the source of public-health problems in factors in the social, economic and political environments that shape and constrain individual, community, and societal health outcomes. (Academy for Educational Development Center on AIDS and Community Health)
**Syringe Exchange Programs (SEP):** A way for injection drug users to safely dispose of used syringes and to obtain sterile syringes at no cost. In addition to exchanging syringes, many SEPs provide a range of related prevention and care services that are vital to helping injection drug users reduce their risks of acquiring and transmitting blood-borne viruses as well as maintain and improve their overall health. (cdc.gov)

U thru X

**Undetectable Viral Load:** The point at which levels of HIV RNA (ribonucleic acid) in the blood are too low to be detected with a viral load test. This does not mean that the virus has stopped replicating or has been removed from the body entirely, only that the small amount of virus remaining is below the test’s ability to measure it. The viral load below which a test cannot detect the virus depends on the brand of the viral load test.
The Latino Commission on AIDS developed the *Navigating Changing Environments: A Leadership Toolkit* as part of its capacity building assistance work with communities in the Deep South of the United States as well as Puerto Rico and other states with Latino populations. However, the toolkit is meant to be used by community organizers, advocates, healthcare providers, community-based organizations, faith-based organizations, and others *that work with marginalized communities impacted by HIV/AIDS* who are looking for examples, approaches and tools utilized by those leaders who have been hard at work mobilizing their communities in a variety of contexts. The Commission recognizes the challenges of working with marginalized and emerging populations moving into, and interacting with, any community. We invite you to use the contact information that follows below. It is our hope that users of this toolkit will provide us with feedback on the usefulness of this resource in their community and the leadership efforts that they undertake.

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Next Section: **Emerging Populations Defined** »

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Emerging populations can be those populations that have yet to achieve institutional power or recognition.

While Latino migration to the Deep South was scarcely noticeable in the 1980s, it increased significantly during the 1990s. NAFTA (1994 North American Free Trade Agreement) and the 1990s economic boom brought Latino immigrants to the deep Southern states to work low-paid, low-benefit or no-benefit jobs. The Southern economy has been restructured to feature car plants in Tennessee, Kentucky, Alabama, Mississippi and South Carolina and food processing for pigs, chicken and seafood all over the rural South. Foreign-born workers came to work in the rural parts of Northern Alabama in hosiery, carpet, garment, textiles, furniture, and plastics manufacturing and produce picking. Chicken farming and poultry processing has become especially concentrated in Alabama, Arkansas, Georgia, and North Carolina.

<table>
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<th>States with Greatest Hispanic Population Growth, 2000-2010</th>
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<tr>
<td>In percent</td>
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<tr>
<td>U.S. Total</td>
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<tr>
<td>South Carolina</td>
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<td>Alabama</td>
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<td>Tennessee</td>
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<td>Kentucky</td>
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<td>Virginia</td>
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Source: 2010 U.S. Census
Population growth created an increase in the service economy in cities like Memphis, as in many other Southern urban centers, where migrants also work in construction and manufacturing. South Carolina’s Latino Population grew by 148% between 2000 and 2010. The Deep South received Mexican and Central American post-Katrina workers, in addition to minorities from within the U.S. The most significant group of laborers were Latino, followed by Southeast Asian groups. By 2007, the populations of Latinos and Asian immigrant groups in New Orleans had grown from 4.5% to 1.3%.

The latest 2010 U.S. Census data reveals a steady growth momentum in the Hispanic/Latino population across the United States. The census data show that Hispanics are the nation’s largest and fastest-growing minority group. The latest state-by-state U.S. Census figures continue to show the incredible double-digit growth the Hispanic population is fueling in states across our country (see table below). In the South, this growth is framed by a health care system unprepared for an influx of people with different cultural values, language use and understandings of disease, health and medical care. Due to a high proportion of the population having undocumented status, the actual number of Latino populations may be much higher than reported. For example, while the 2010 Census reported 13,000 Latinos in Charleston, South Carolina, the actual number may actually be 50,000.

Even within Hispanic communities, differences emerge across immigration, ethnicity, sexuality and socio-economics. In New Mexico – a state that is 50% Hispanic, for instance, the Latino Advisory Group of the state Health Department HIV Program identifies Latino gay and bisexual men as an emerging population. Similarly, Latinos en Acción based in Fort Lauderdale – a coalition of service providers, community members and the health department – consider Latino gay and bisexual men a considerable emerging population on whom to focus their efforts.

Acknowledging these differences and how they may impact service accessibility is a key component to the work of Latinos in the Deep South Program. One common barrier is recruitment of community members into clinical and prevention services. Another is the implementation of culturally and linguistically appropriate services when funding may not support it yet.

Next Section: Latinos in the Deep South Initiative »
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The following is an introduction to the Latinos in the Deep South initiative, which developed the toolkit, and on whose experience the toolkit’s framework is based, as well as an attempt at characterizing emerging populations.

The Commission started the Latinos in the Deep South initiative in 2007 in recognition of the rapid increase of Latino populations in U.S. Southern states. Latinos in the Deep South focused initially in seven states: Louisiana, Mississippi, Alabama, Tennessee, Georgia, South Carolina and North Carolina. Within the first two years, the Commission conducted roundtables in each state to collect data and begin the process of bringing health departments and service providers together to look at HIV programs that focus on this emerging population. With foundation support, the Commission’s Latinos in the Deep South initiative successfully produced a report that highlighted challenges, successes, partners and agenda building processes to move forward on providing a continuum of HIV education, prevention, testing and treatment to Latinos across the region.
The main findings of the two-year investigation were:

- Throughout the region HIV infection and AIDS cases are rising at an alarming rate among Latino populations while prevention education lags behind. Access to HIV-related medical care is complicated by fear, stigma and, for the undocumented, a variety of administrative, practical and legal obstacles.

- Latinos often discover they are HIV-positive only at a late stage of infection as a result of serious illness or through pre-natal screening. In many communities pregnancy-related care is the main avenue for detecting cases of HIV among Latinos, including men.

- Many Latinos in the South, especially recent immigrants, do not have access to health care and are not reached by health promotion activities.

- AIDS prevention and service organizations throughout the region are making efforts to establish contact with Latino communities even without Spanish speaking employees.

- The high level of transience among the Latino and immigrant communities complicates attempts to carry out traditional HIV prevention initiatives based on peer-to-peer education.

- The increasing visibility of anti-immigrant sentiment makes Latinos distrustful of health departments and medical providers, which weakens campaigns to promote public health.

- Medical care for those infected with HIV is often available; however, undocumented clients have additional burdens in managing the disease.

- The lack of trained bilingual professional staff inhibits prevention initiatives and delivery of care; the few bilingual workers now in the field are overstretched and expected to fulfill too many roles.

- A well-organized and -marketed commercial sex industry generates a risk environment both for immigrant men and for the sex workers providing the services.

- High birth rates among Latinos have led to a massive increase in Spanish-speaking public school enrollment, which makes more urgent the need for appropriate educational programs for parents and for Latino adolescents in the region.

- Interventions targeting gay Latinos or other Latino men who have sex with men are rare in the South.

Since then, the program has evolved into different branches: capacity building assistance (CBA), community-based participatory research (CBPR), and community organizing. These have grown organically in response to the various needs in the region. The Commission recognizes that the HIV service infrastructure is not as well developed in the U.S. South as in the original national epicenters of the epidemic. This complicates service delivery for Latinos – who, in some states, are highly migratory. In other states,
where there are more established Latino communities, services are still mitigated by the availability of bilingual and culturally appropriate services. In most regions, the local partners recognized that ongoing community assessments, development of coalitions of service providers, and non-traditional partners are integral to meeting the need for Latinos in the region.

As a CBA program, the Commission has supported the growth, strategic planning and actions of coalitions and organizations serving the local Latino populations across the South. While community organizing is important, infrastructure issues remain a challenge in the region. As a CDC-funded CBA provider, the Commission has been heavily involved in coalitions and activities in the original seven states and expanded to include Kentucky, Florida, New Mexico and Arkansas. The Commission recognizes that the lessons learned and best practices developed within the original seven states have relevance to other regions that have emerging Latino populations.

In CBPR, the Commission recognizes that academic researchers, health departments and service providers all have to stretch to meet in common ground to meet the data collection, intervention design and policy development to effectively service Latinos in this area. With the support of the Office of AIDS Research, the Commission has convened CBPR summits in Alabama, Arizona, North Carolina, Missouri and Tennessee. These have involved over 200 elected officials, researchers, health department representatives, service providers and community members.

The community organizing function of the Latinos in the Deep South Program emerged specifically to encourage, enhance and act on policy issues in the Southern states. One of the key elements has been a distance-based learning initiative called the Dennis de León On Sustainable Leadership Institute, which completed its first cohort in 2011. The Institute was named after the Commission’s visionary founder, Dennis de León, who believed in a just society, especially for those living with HIV/AIDS. As an attorney, Dennis understood that policy and service providers have an obligation to the local community. The Dennis de León Sustainable Leadership Institute is conducted through webinars and local projects that are tailored to each participant and location. The Institute focuses on how to identify problems and affect real policy change. In the past, this has meant a focus on AIDS stigma, HIV criminalization, HIV funding, anti-immigration sentiment and syringe access.
The Commission recognizes that HIV sero-incidence is increasing in the Southern states, along with the number of Latino populations moving into the regions. The tables below indicate the sero-prevalence of states and metropolitan statistical areas (MSAs) next to the sero-incidence of MSAs in the U.S. in one year. Whereas those states and locales with long-time epidemics clearly maintain a majority of HIV cases, the data clearly points to an increase in the rate of new infections, as nine of the top ten sero-incidence rates occur in Southern states.

Through these three branches, the Latinos in the Deep South Program provokes and encourages real change to occur at a local level. The combination of factors requires a multi-pronged response – including CBA, CBPR and grassroots community organizing. The Commission is proud to share these lessons learned and best practices, and hopes to illustrate how these can be replicable in other regions and sustainable in the South.