HIV/AIDS Stigma

Finding Solutions to Strengthen HIV/AIDS Programs
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HIV/AIDS Stigma: Finding Solutions to Strengthen HIV/AIDS Programs

ICRW at Work

HIV/AIDS-related stigma has long been recognized as a crucial barrier to the prevention, care and treatment of HIV and AIDS. Yet not enough is being done to combat it. One reason has been a lack of information: How do we define stigma? Can stigma be measured? Another reason has been the assumption by development practitioners that stigma is too tied to culture, too context-specific and too linked to taboo subjects like sex to be effectively addressed. Action also has been impeded by a lack of tools and tested interventions.

Seminal research by ICRW and in-country partners on HIV/AIDS stigma coupled with the development of tools to combat stigma and indicators to evaluate the effectiveness of stigma-reduction efforts represents significant progress in both filling information gaps on stigma and dispelling myths that stigma cannot be addressed or measured.

Evidence from an ICRW-led multi-country study conducted from 2001-2004 in Ethiopia, Tanzania, Vietnam and Zambia shows that HIV/AIDS-related stigma is far less varied and context-specific than assumed. In fact, the key causes of stigma, its impact and its consequences have many more similarities than differences across contexts. Using findings from the four country studies, ICRW and its partners developed an HIV stigma-reduction toolkit for people working in communities to combat stigma. This toolkit is a crucial asset for HIV/AIDS and other health programs because it provides
“Everyone is now mobilized around universal access [to antiretroviral therapy], which is great—universal access by 2010 is a good goal. But no one is talking about the fact that to reach this goal we need to eliminate stigma, shame, denial, discrimination, inaction and misaction before 2010.”

Canon Gideon Byamugisha, an HIV-positive clergyman who co-founded ANERELA+, the African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS.

Defining Terms:
What is HIV/AIDS-related Stigma?

HIV/AIDS-related stigma and discrimination is a “process of devaluation” of people either living with or associated with HIV and AIDS, according to UNAIDS (www.unaids.org). This stigma often stems from the pre-existing stigmatization of sex and intravenous drug use—two of the primary routes of HIV infection. Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status. Discrimination occurs when a distinction is made about a person that results in him or her being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group (UNAIDS 2003).
Common Causes, Similar Consequences

Findings from ICRW-led Research

ICRW’s research on stigma and discrimination, conducted from 2001 to 2004 in urban and rural sites in Ethiopia, Tanzania, Vietnam and Zambia, and again in Tanzania from 2004 to 2005, found that even across these different settings, stigma shares several core causes and consequences. The research also revealed that women bear a disproportionate share of blame for HIV and are more harshly condemned.

*Stigma Stems from Misinformation* . . .

*Myth: HIV Can Be Transmitted Through the Air.*

*Finding: People Fear Casual Transmission.*

HIV is often thought to be highly contagious. Based on this assumption, people often suspect that individuals with HIV or AIDS pose a threat to the community at large. This misconception is not limited to the general population. In several cases, research has shown medical personnel to be misinformed, especially about how HIV is, and equally as importantly, is not transmitted.

In Ethiopia, Tanzania, Vietnam and Zambia, people commonly expressed the fear that HIV could be transmitted through ordinary, daily interactions with people living with HIV or AIDS, and that no exchange of body fluids was needed for transmission to occur. People cited fear of transmission
through casual contact with an HIV-positive person, such as touching, eating food prepared by someone with HIV or AIDS, breathing “infected” air or sharing items such as clothing, bedding or eating utensils. The 2004-5 Tanzania study confirms that these fears are deeply embedded: When presented with 12 scenarios of casual contact, nearly half of people surveyed among the general population cited at least one situation where they feared they could contract HIV through casual transmission. Exposure to saliva rated as the most common fear.

Fear of transmission through daily casual contact leads directly to stigma in the form of isolating people with HIV or AIDS. As an Ethiopian woman explained, “Some people in this community believe that HIV/AIDS transmits through kissing, shaking hands, sleeping together [in the same room] and eating together with an infected person. Due to this, they isolate the person from the community.”

... and Bias

Moral Judgment: People Who Get AIDS Did Something To Deserve It.

Finding: Values, Norms and Moral Judgment Play an Important Role in Fueling Stigma.

HIV/AIDS-related stigma is fueled by assumptions about the moral integrity and values of people with HIV or AIDS. Socially and personally, people tend to associate AIDS with moral impropriety. In the four countries studied, HIV infection was commonly perceived as the result of a personal choice—one chooses to engage in “bad,” risky behaviors and, therefore, is at fault if he or she becomes infected. A religious leader in Zambia who discussed HIV-positive patients in a local clinic said, “Those patients are promiscuous . . . careless with themselves. God is punishing them for disobedience . . . the diseases are not traditional in nature and those affected are examples of what God can do to those who disobey His commandments.” The 2004-5 Tanzania study further supports these findings. More than half of people surveyed among the general population agreed with at least one of three stigmatizing “shame” statements, such as feeling that people with HIV or AIDS should be ashamed of themselves. More than 65 percent agreed with at least one of four stigmatizing “blame and judgment” statements, including that HIV and AIDS is a punishment for bad behavior.

Fear of Stigma Can Lead to Failure in HIV/AIDS Prevention, Treatment and Care

People with HIV or AIDS often fear the stigma that may result if others know that they are HIV-positive or have AIDS. This fear has a profound impact on the effectiveness of HIV/AIDS prevention, treatment and care programs because people who are infected may be reluctant to use these services. Qualitative data suggest that fewer people may seek HIV testing because they fear a positive test result, which in their minds is linked to the stigma and social repercussions that they will experience if they test HIV-positive. People who do get tested might not return for their results for fear of being seen at a clinic known to test for HIV, which could raise suspicions about their health.

Stigma also affects people’s willingness to disclose a positive test result to others, including their spouses. In all four countries, people with HIV struggled with the issue of disclosure. In some cases, people know that they have HIV for years but do not tell even their most intimate partners for fear of stigma and its consequences, which can include physical violence and abandonment. This finding is further borne out in the 2004-5 Tanzania data: Among HIV-positive men and women surveyed who have a partner or spouse, the average time before disclosing their status was nearly three years (two years and 11 months). The delay can have serious repercussions for preventing further transmission of the virus. Researchers interviewed a woman with HIV who had continued to have sexual relations with her husband without condoms and gave birth to a child without avail-
Fears Realized for People with HIV and AIDS

Isolation

Physical isolation of people living with HIV and AIDS is widespread. It ranges from isolation within the home and in such community gathering places as tea shops, markets and places of worship to workplaces, schools and hospitals. In the home, stigma is expressed through the segregation of typically shared objects like eating utensils, clothes and bed linens and by making people with HIV and AIDS sleep and eat in isolation—highly unusual actions in all four study countries where space is limited and eating together is the norm. Research showed that people are reluctant to sit next to a person with HIV in public places or they will move away if they realize they are sitting next to a person with HIV. As a woman in Zambia explained, “No one would sit next to you [on the bus] … maybe you cough and everybody [has] their eyes on you.”

Exclusion from Social Networks

People with HIV often find that they are no longer welcome at important family and community events, such as weddings. In the realm of daily life, they often find that their friendships wane or disappear and that neighbors, friends and relatives are reluctant to visit or to lend or borrow common household implements and food items, important coping strategies in poor communities.

Similarly, HIV-positive people lose power, respect and identity through the taking away, or diminishing, of their roles, responsibilities and social standing within the family and larger community. This expression of stigma is a result of both the assumption that HIV was contracted through inappropriate behavior as well as the belief that HIV means immediate disability and death. As stated by a Tanzanian man, “When they see that someone has HIV, they see him as already dead.”

Insults and Gossip

People with HIV often endure insults, taunts and name-calling. In addition, derogatory and demeaning language is often used to talk about or label people with HIV and AIDS. In Tanzania, for example, a person with advanced AIDS is described as maiti inayotembea or “walking corpse.” Gossip and rumors focus on speculation about whether a person has HIV, usually because of visible signs of illness or association with “high risk” groups.

Once a person is assumed HIV-positive, people often speculate about how he or she contracted HIV. Gossip was reported to be one of the most significant forms of stigma, particularly for women. As this woman living with HIV in Ethiopia noted:

Let me tell you from my experience. In our village, I am the only woman who is suspected for having the virus. However, many men are suspected and known for having the virus. But nobody seems concerned and talks about the men. They spread gossip about me.

Other forms of verbal stigma include expressions of blame and shame, often through scolding or judgmental statements like “they got what they deserved.” People living with HIV and AIDS are blamed for becoming infected with HIV through their “irresponsible” and “selfish” behavior; bringing shame to themselves, their families and the community; and becoming a burden to the family.

Loss of Livelihood

People with HIV and AIDS in the four countries studied reported that one of the most profound consequences of stigma was its impact on their ability to earn a living. People in formal employment found themselves being dismissed upon disclosure of their HIV status, and mar-
ket vendors found their client base declining. Participants in the Ethiopia study reported that domestic workers with HIV almost always were dismissed.

Poor Care within the Formal Health Sector and at Home

People with HIV were found to receive inferior care or to be denied care altogether. A nurse in Ethiopia explained, “The wards don’t have gloves, so how would you expect a nurse to go and attend to a HIV/AIDS patient? That’s why you can find a patient lying in a pool of diarrhea for many hours.”

In households, HIV/AIDS-related stigma can result in the neglect of people who depend on care due to the caregiver’s fear of transmission, anger or moral condemnation, fear of experiencing stigma by association or a combination of these factors. Poverty and resource constraints often further limit the amount of care a family is able—or willing—to provide. Caregivers also frequently experience burnout, particularly as HIV-disease advances and the burden of care becomes increasingly demanding.

Women Held to a Double Standard

All ICRW-led studies found that women tend to endure more HIV/AIDS-related stigma than men. In the most recent study, conducted in Tanzania in 2004-5, nearly two-thirds of women with HIV reported experiencing stigma in the past year, as opposed to slightly less than half of men. Why? Women are expected to uphold the moral traditions of their societies. And communities view HIV status as evidence that these women are failing to uphold that moral imperative.

A fundamental double standard exists, where men generally are expected to be reckless and adventuresome and, as a consequence, more likely exposed to sexually transmitted infections (STIs), including HIV. Conversely, women are expected to be sexually faithful, chaste and morally upstanding. A 2000-3 qualitative study by ICRW and partners in Tanzania sheds further light on this double standard, revealing that men with HIV are excused for breaking sexual norms, while women are blamed and labeled.

In Vietnam, women are expected to put their families first, with the highest priority on their roles as wives and mothers. A woman using drugs (regarded as undermining both the reputation and economic well-being of families) or involved in sex work (said to “break the family’s happiness”) is strongly judged and simply not tolerated; HIV infection is considered evidence of such unacceptable behavior.

In Ethiopia, Tanzania and Zambia, women with HIV tend not only to be more stigmatized for having “failed as proper women,” but also blamed for “bringing” HIV into a family or marriage. As an HIV-positive woman in Zambia explained, “The word ‘disgrace’ is used more on women. . . . People say women are the ones who bring sickness most of the time. They are the ones who start [the illness].”

Women Experience More Severe Stigma

“… If men are still young and they indulge in play and get infected [with HIV], that’s the general story of society. If a girl gets this disease, no one would like to get close to her, because it is a problem of her conduct and her morality. It is not tolerated in females compared to males.”

Female community counselor in Vietnam.

Source: Survey of 218 people living with HIV and AIDS in Tanzania, 2005
Overcoming Information Gaps, Social Fears

Overcoming common doubts and fears about HIV and neutralizing the deeply ingrained tendency to judge people with HIV and AIDS are crucial steps for any program working to reduce HIV-related stigma. Including people with HIV and AIDS in key, prominent roles in these programs will add immense value to these efforts.

Build Knowledge about HIV and AIDS

The persistence across diverse settings of “knowing, but not quite believing” that HIV cannot be casually transmitted indicates that overcoming doubts and fears is a key step for any program working to reduce HIV-related stigma. The continuation of stigma driven by these fears, despite years of imparting information about how HIV can be transmitted, indicates that programs need to focus on the substantive content of messages pertaining to HIV as well as the style and method of delivery. Findings from ICRW-led studies suggest that programs need to improve the content of messages pertaining to HIV, providing information not only on how HIV is transmitted, but also how it is not transmitted. This and other HIV/AIDS information also should be provided in an interactive forum, moderated by a knowledgeable and trusted facilitator. Such an environment will help encourage discussion and questions, and allow the facilitator to address all individual concerns and unambiguously dispel the notion that HIV can be transmitted through casual contact. People who understand and internalize this fact—and the reasons for it—will be less likely to stigmatize AIDS-affected people through avoidance and isolation.

Create Stigma-free Messages, Safe Discussion Spaces

Programs can help to eliminate stigma by delinking HIV from the sensitive and often taboo social issues that are associated with its transmission, in particular sex and intravenous drug use. This delinking can be done without sacrificing effective communication of information about prevention. For example, messages, programs and policies should discuss the behaviors that can lead to HIV transmission without direct reference to particular individuals or groups to avoid the temptation to single out these groups as “vectors” of transmission.

Also because people may be uncomfortable discussing some of the norms and values typically associated with HIV and AIDS, it is important to create safe spaces with a trusted facilitator for people to openly discuss their fears and opinions that can lead to stigmatizing behavior.

Involve People with HIV and AIDS

People with HIV and AIDS must play a central role in stigma reduction and program development. Bearing the brunt of stigma, they have the life experience and knowledge needed to design and implement appropriate stigma-reduction responses. In particular, they can help combat the fear of casual transmission of HIV, the belief that HIV means immediate disability and death, and the feeling that people with HIV are somehow different from everyone else. For many, the ability to contribute to the fight against HIV/AIDS-related stigma is life-affirming in itself.

Pham Thi Hue

is a young woman living with HIV who has established a support group for other women living with HIV in Hai Phong.

“Being involved in various activities of ISDS [ICRW’s partner in Vietnam], I felt a great relief,” Hue says. “I no longer wanted to hide my positive status. The disclosure helped me to overcome self-stigma and it was a magic medicine that made me confident and strong.”

In 2004, Hue was awarded Time magazine’s Asian Hero award for her work as a painter and her support of children in Vietnam who are HIV-positive.
Taking Action to Combat Stigma

A Toolkit to Reduce Stigma

The initial stigma studies in Ethiopia, Tanzania and Zambia exposed a pressing need for a concrete set of tools and strategies to help HIV-affected communities and development workers identify and tackle stigma. Using the research findings and lessons learned as a guide, in 2003 a wide range of stakeholders, including ICRW’s research partners and more than 50 local organizations from the three countries, worked together to create a stigma-reduction toolkit. The toolkit, designed for nongovernmental organizations (NGOs), community groups and HIV educators, provides practical tools to use in stigma-reduction interventions among groups in communities poised to effect change, including religious and political leaders, health workers, people with HIV and AIDS, and community members. Participatory exercises address the knowledge gaps and values that underlie stigma. The toolkit tackles stigma from the perspective of both the “stigmatizer” and the “stigmatized,” encouraging people to reflect on their stigmatizing attitudes and behaviors, and providing people with HIV and AIDS and their families space to examine stigma and develop skills and strategies to deal with it.
Measuring Stigma Quantitatively

As efforts grow to address stigma and discrimination, so does the need for a set of standard tested and validated stigma and discrimination indicators. Indicators are a key tool for identifying effective anti-stigma programming: By providing a standardized way of describing and measuring stigma across different environments, they offer a means to evaluate programs and identify what works to reduce stigma.

To begin the process of developing indicators, ICRW researchers and partners turned to the four country studies, which had isolated the causes and common manifestations of stigma. This was followed by a 10-month study in Tanzania to test and validate a set of indicators measuring stigma in four key dimensions: fear-driven stigma, value-driven stigma, enacted stigma (stigmatizing actions), and disclosure of HIV status. These dimensions were tested and validated among three populations—health care providers, people with HIV and AIDS, and the general community—resulting in a recommended set of indicators. ICRW is continuing work to refine these indicators and test how well they capture changes in stigma over time.

Understanding and Challenging HIV Stigma:

**Toolkit for Action**

The lack of tools to guide responses to stigma has hampered and delayed action against AIDS. To address this, ICRW, CHANGE/AED and their partners developed a toolkit, “Understanding and Challenging HIV Stigma: Toolkit for Action.”

The toolkit assists efforts to:

- Increase stigma visibility and assist in resolving contradictions, such as those between good intentions and stigmatizing behavior, for example, wanting to comfort a person with HIV or AIDS, but then refusing to touch him or her;
- Enhance practical knowledge to reduce fear of casual transmission;
- Provide a safe forum to discuss such sensitive topics as sex, death, drug use and inequity;
- Find a common language to talk about stigma;
- Strengthen the capacity of people with HIV and AIDS to challenge stigma;
- Provide a process to determine appropriate and feasible individual and community responses to stigma; and
- Provide comprehensive, flexible tools for organizations to strengthen staff skills and develop or strengthen interventions to reduce HIV-related stigma.

The first edition of the toolkit was developed in Africa and is available in Amharic, English, French and Kiswahili. An adaptation of the first edition has been completed and is available in Vietnamese. The entire toolkit can be found at: www.changeproject.org.
Developing, Testing and Evaluating Stigma-reduction Efforts

ICRW is working in India, Mozambique, Tanzania and Vietnam to design, implement and evaluate programs, using both the stigma indicators and toolkit to guide these efforts. This work is taking place at the community level, in health care provider settings and with media.

Work with Communities

Following up on stigma research in Vietnam, ICRW is continuing collaborative work with its in-country partner, using the toolkit to develop and implement a series of interventions in two communities, one in the north and the other in the south. Activities include presenting awareness-raising workshops on HIV/AIDS-related stigma for Communist Party institutions, government agencies and “mass” organizations, and training provincial-level staff in Communist Party institutions and government agencies to use the stigma toolkit to train local community leaders on stigma reduction. After attending facilitated, participatory action-planning workshops, community leaders developed their own stigma interventions, with ICRW’s in-country partner providing guidance as needed and ICRW assisting in the evaluation of implementation and outcomes.

ICRW also is assisting efforts to integrate stigma reduction into the activities of community-based organizations already working on HIV and AIDS and other community health concerns. In Tanzania, ICRW, in collaboration with a local partner, is using the stigma indicators to evaluate a community-based stigma-reduction program being undertaken by Kimara Peer Educators, a community-based organization that offers HIV prevention, care and support activities through the training of staff and volunteers in stigma-reduction. Preliminary evidence suggests that Kimara’s stigma-reduction program has led more people to attend counseling and receive HIV/AIDS testing. More people with HIV and AIDS also have joined group counseling sessions. ICRW and its partner now are using the stigma indicators to evaluate the organization’s program to determine if stigma has declined in the community. Key lessons learned from this evaluation will be distilled to identify effective stigma-reduction models to replicate and scale up.

In Mozambique, ICRW is helping to incorporate stigma reduction into a CORE Initiative project that is integrating tuberculosis (TB) and HIV diagnosis, treatment and care. As with HIV and AIDS, the stigma that surrounds TB often prevents people from seeking potentially life-saving services. With this understanding in mind, the project is including stigma awareness-raising and anti-stigma training for health staff and community volunteers, who also will be involved in developing and implementing specific interventions to tackle both HIV/AIDS and TB stigma in their work.

In Andhra Pradesh, India, research suggests that the effectiveness of AIDS prevention and control programs are undermined not just by stigma, but also by women’s fear of violence, which acts as a barrier to their ability to negotiate protection, seek services, or leave abusive or risky relationships.

To address both factors, ICRW, in collaboration with two local NGOs, designed and field-tested a pilot toolkit—adapted from the original stigma-reduction toolkit—for HIV/AIDS prevention programs to work with communities to address stigma and gender-based violence. This toolkit was developed in collaboration with mobile populations—truckers and people who interact with truckers (sex workers, truckers’ spouses and truckers’ helpers)—both because they tend to bear the greater brunt of stigma and violence, and because they are at a higher risk of contracting HIV than the general population. A pilot application of the toolkit with the sex workers, truckers’ spouses and truckers’ helpers shows...
promising outcomes: Condom use increased significantly, nearly one-third of participants reported more accepting attitudes toward people with HIV and AIDS, and half reported a decreased tolerance of violence against women. Involving the community throughout the project yielded similar results, in addition to helping individuals feel more comfortable publicly discussing such traditionally taboo topics as AIDS, sex and violence—topics that must be addressed in AIDS prevention efforts.

Work with Health Care Providers

Health care settings—often the first point of contact for people with HIV and AIDS—have been found to be a common locus for stigma and discrimination against people with or suspected of having HIV or AIDS.

Building on the early success of the stigma and violence reduction toolkit in Andhra Pradesh, ICRW now is addressing these issues with health care workers at the community level, again in Andhra Pradesh. ICRW and a local partner will mirror the process undertaken with mobile populations, working with formal and informal health care providers—including certified doctors, registered and unregistered health care practitioners, community health workers, and traditional birth attendants—to create an intervention and toolkit to reduce their stigmatizing behaviors and address gender-based violence as a public health issue. Capitalizing on the respect and trust health care providers have within communities, they are learning effective ways to communicate to community members that stigma and violence are unacceptable and at the root of the worsening epidemic.

In Vietnam, ICRW and partners are implementing and evaluating a “control” and “test” site for stigma-reduction interventions in health care settings. The “control” site will educate health care workers on modes of HIV transmission and preventive measures to reduce transmission. The “test” site includes the education component and adds social stigma-reduction activities.

Health care settings—often the first point of contact for people with HIV and AIDS—have been found to be a common locus for stigma and discrimination against people with or suspected of having HIV or AIDS.

The project will compare the interventions by examining differences between the groups in knowledge about transmission of HIV, attitudes toward people with HIV or AIDS, discriminatory behaviors (such as refusal to treat HIV or AIDS patients), and the extent to which HIV/AIDS patients report stigmatizing behavior among health care providers.

Work with Media

Also in Vietnam, ICRW and a local partner are working with the Central Commission for Ideology and Culture—the government body responsible for vetting all media and serving as the conduit of government social policy—to create national guidelines for reporting on and discussing HIV and AIDS in a non-stigmatizing way. The guidelines will be designed for use by media and others who communicate and educate on HIV and AIDS, covering topics such as language use; delivery of accurate and precise information on transmission, risks, prevention, treatment and care (rather than vague and sensationalized stories); and how people with HIV and AIDS should be represented in the media. Though compliance to the guidelines will not be formally monitored, the government practice of reviewing and censoring all media content before release means that items not conforming to the guidelines likely will be rejected for publication or dissemination.
Looking Forward

While slow in coming, stigma’s pernicious effect on the HIV and AIDS prevention, treatment and care efforts is finally being recognized. Initial efforts to combat stigma and discrimination are promising. Building on this recognition and the momentum of past and current stigma reduction efforts, ICRW anticipates continuing to develop and evaluate stigma-reduction interventions and using and adapting the toolkit as needed for new populations and settings. Work also will continue to test the current set of indicators in different settings and develop additional indicators for new populations to solidify a global set of standardized stigma indicators. Together, these efforts could pave the way to developing a model for scaling up stigma reduction.

Further research also is needed to examine layered stigma—a problem revealed in earlier research where HIV-related stigma occurs in conjunction with other social stigmas, such as those associated with commercial sex work or injection drug use—and explore potential interventions for marginalized populations. ICRW’s research is ongoing, and plans are underway to further develop interventions that address the link between stigma and violence.

With the increasingly refined ability to measure stigma and its reduction through the use of standardized stigma indicators, ICRW is looking to explore more complex relationships between stigma and HIV/AIDS prevention and treatment efforts. Some critical questions include the following:

- Does the provision of treatment reduce stigma?
- Will a decrease in stigma within communities increase uptake of HIV-related treatment and testing, and such preventive behaviors as disclosure to sexual partners or increased condom use?
- What are the implications of stigma and gender norms for microbicides and vaccines? For instance, how do they influence participation in clinical trials?
- If microbicides and vaccines become widely accessible, will stigma and gender roles factor into decisions to use them?

Stigma is certainly complex and affected by context. But with an increasingly sophisticated understanding about the nuances of stigma and the tools to address and measure it, development workers and affected communities are better poised to reverse stigma’s devastating impact on people infected with and affected by HIV and AIDS.

“Ending the AIDS pandemic will depend largely on changing the social norms, attitudes and behaviors that contribute to its expansion. Action against AIDS-related stigma and discrimination must be supported by top leadership and at every level of society . . . .”

UNAIDS 2006 Report on the Global AIDS Epidemic
For more detail on the research cited in this paper, contact Laura Nyblade (lnyblade@icrw.org) or refer to the following publications at www.icrw.org:


