



Community Education Group, Inc. (CEG) is a 501(c)3 not-for-profit agency dedicated to social change focusing on the creation and expansion of programs and projects which address the health, socio-economic, environmental, and systemic challenges facing the African American family.

727 8th Street SE
Lower Level – Side Entrance
Washington, DC 20003
(p) 202.543.2376 (f) 202.543.2498
(w) communityeducationgroup.org

The Exchange

Building a Coalition to Attend to Public Policy Issues
Facing African American Women and their Families with HIV/AIDS



72%

THE PERCENTAGE OF NEW HIV INFECTIONS AMONG ALL WOMEN THAT ARE AMONG AFRICAN AMERICAN WOMEN

Executive Summary

Women are often only considered as a secondary or tertiary priority area, even though the figures for HIV/AIDS and poor health outcomes have been increasing at alarming rates in recent years among our nation's women. Oftentimes, when we focus on the needs of the female population, we are led to considering structural issues, with a wider scope of challenges. It is only with a national coalition that we will be able to channel strengths, reinforce partnerships, increase information flow and information sharing, develop leadership, and create awareness and space for effective change.

Community Education Group (CEG) has taken the initiative toward creating a national coalition, called the Exchange, to do work around

domestic HIV/AIDS issues, particularly serving African American women, their families, and their communities. The Exchange will forge an understanding of our common ground so that we can all more effectively advocate for the needs of African American women. In 2004, CEG conducted formative research through national conferences and surveyed care providers, health specialists, and social and behavioral scientists from community-based organizations, clinics, government offices, and universities. CEG set out to find what the priority areas for others were, who would be interested in joining a coalition, and what effective work a coalition might be expected to accomplish. Through the 1,186 participants, we discovered

that some of the top ranking issues that affect African American women and their families at risk of or living with AIDS such as lack of health care, lack of access to affordable treatment and presence of unknown partner risk.

It was found that 613 of the respondents were willing to build a coalition with other public health representatives to advocate on behalf of African American women and their family at risk of and living with HIV/AIDS. When each organization type was broken down individually, it became clear that CBOs and clinics were most supportive of building a coalition (with 88% and 90% willing to build, respectively). Government agencies and universities were both slightly lower,

though still the majority, at 66% and 68% respectively. Reasons behind the willingness to build a coalition included the need to attend specifically to the health factors that plague African American women and their communities. Secondly, many respondents motivation was to be able to provide a holistic, collaborative and interconnected approach to African American women's health. When asked choose from a list of possible policy and advocacy intervention to focus the coalition, the respondents selected access to health care, prevention messages and access to affordable treatment as the top three areas that a coalition of representatives should focus their advocacy for African American

women. The vast majority, 96.7%, of participants believed that the coalition would provide effective advocacy for addressing public policy issues facing African American women. Among points that were mentioned were: the collective voice for advocacy and empowerment, addressing women's health concerns, reducing risk of HIV among African American women and providing overall better service.

Larger organizations and government officials tend to miss many issues that influence the clients we serve and the frontline organizations we work within. This reality was illustrated during the recent 2004 Vice Presidential debate when moderator Gwen Ifill, asked the following question:

"I want to talk to you about AIDS. And not about AIDS in China or Africa, but AIDS right here in this country where black women between the ages of 25 and 44 are 13 times more likely to die of the disease than their counterparts. What should the government's role be in helping to end the growth of this epidemic?"

Neither candidate was able to provide a swift, direct, or cogent answer. Both admitted to lacking awareness of the impact on African American women.

President Bush, in his State of the Union Address in 2005 was clear about prioritizing HIV in African American communities domestically. In his address, he said, "We must focus our efforts on fellow citizens with the

highest rates of new cases, African American men and women." We are now in a critical time where the topic has been brought to the forefront, and now we must take action.

There are three simple action steps I am asking each of you to consider.

- 1. Read and share "The Exchange Booklet."** We have taken the first step and created this booklet that summarizes top priority areas for issues that face African American women and their communities, as well as top advocacy areas. By reading this booklet and sharing it with others, we enter into the larger scope of health and what we are able to accomplish and provide for our communities.
- 2. Fill out the cards to the Senate and the House of Representatives.** We must ensure that policy makers are educated about the health issues that influence our families and the constituencies we represent and work with. This project needs your voice. It will only take one moment to fill in your name and address on each card, but it will become part of a lasting impact on the health disparities in our nation.
- 3. Fill out a card to be listed as a member of The Exchange National Coalition.** We would like to build a formal membership base for this national coalition that will seek to address issues that surround HIV and AIDS

among African American women. Thank you for your support.

25

THE NUMBER OF TIMES MORE LIKELY AN
AFRICAN AMERICAN WOMAN THAN A WHITE
WOMAN IS TO GET DIAGNOSED WITH AIDS

Introduction

Community Education Group, Inc. (CEG) is a 501 (c) 3 not-for profit agency. Dedicated to social change and the creation and expansion of programs and projects; CEG addresses challenges facing African American women and their families. Since its inception in 1996, CEG has enhanced its clients' ability to provide effective public health programs and services. Additionally, CEG works to ensure that marginalized communities are in the forefront of creating change. CEG currently offers a variety of services including:

1. Training & Technical Assistance
2. Social Marketing & Media Outreach
3. Community-Based Research and Evaluation

In keeping with our organizational motto and mission "Building Stronger Communities One Project at a Time" CEG continually seeks an array of avenues to attend to the increasing rates of HIV infections among African American women. According to the National Vital Statistics Report 2003, AIDS is the leading cause of death among African American women ages 25-34 (Anderson and Smith, 2003). African American women represent approximately 72% of all new HIV infections among women in the United States from 1992-2002 (CDC, 2002).

Numerous studies have attributed the high rates of HIV among African American women to injection drug use and high risk sexual behavior (CDC, 2002 and DC,

Department of Health, 2004). Systemic issues such as poverty, community norms regarding substance abuse, domestic violence, and limited access to culturally competent HIV and health care services also contribute to high infection rates (Office of Minority Health, 2005). Although both structural and individual barriers are attributed to the continuation of the disturbing trend of HIV/AIDS among African American women, government leaders and health institutions have largely ignored the systemic impact of AIDS in this community.

For the future health initiatives of African American women, CEG believes that it is vital that policy makers be informed about and strongly encouraged to address the

1186

THE NUMBER OF SURVEYS
THAT WERE FILLED OUT,
COLLECTED, AND ANALYZED FOR
THE EXCHANGE PROJECT

major health issues devastating African American women, their families, and communities. To better serve African American women and their families infected and affected by HIV/AIDS, CEG assessed 1,186 public health professionals' perceived gaps in HIV/AIDS services targeting African American women. Additionally, CEG assessed these public health professionals' willingness to participate in a national coalition to address public policy issues facing African American women and their family at risk of and living with HIV/AIDS.

Methods

One thousand one hundred and eighty six (1,186) surveys were collected from three public health conferences in the Southern and Northeastern region of the United States. Of the 1,186 participants, 621 AIDS workers (physicians, case managers, public health workers and advocates) came from the 2004 United States Conference on AIDS (USCA), in Philadelphia, PA. Similarly, 545 research participants of approximately 13,000 public health professionals attending the 132nd American Public Health Association (APHA) Conference in Washington, DC were included in the study. And finally, 20 surveys were collected from Dare to Act, an annual conference which brings trauma survivors, researchers, practitioners and policy makers to Baltimore, MD to

work to create change (Table 1).

The data gathered from the Dare to Act Conference, USCA and APHA were collected through convenient non-randomized sampling. Each participant was asked to complete a short survey consisting of 14 closed and open ended questions. Seven (7) questions (3 closed- and 4 open-ended), inquire about the participants' significant organizations, such as the organization's name and address, the type of organization, number of full time and volunteer staff, the gender, race/ethnicity and age of their primary constituents, the participant's primary position, the organization primary activity and primary area of focus. In addition, the participants were asked 7 questions regarding the top systemic and

behavioral issues facing African American women, their willingness to build a coalition to address African American women's health issues, possible policy agendas that such a coalition should place their advocacy focus, the possible effectiveness such a coalition and their interest in learning more about the coalition.

Before the construction of the research database, each open-ended question was coded and converted into quantitative answers. The data were assessed through bivariate and multivariate analysis.

Table 1: Site that Survey was Obtained

SITE	FREQUENCY	PERCENT
USCA	621	52.4
APHA	545	46.0
Dare to Act	20	1.7
Total	1,186	100.0

#1

THE TOP RANKING ISSUE THAT FACES AFRICAN AMERICAN WOMEN AND THEIR FAMILIES AT RISK OF AND LIVING WITH HIV/AIDS, AS REPORTED BY RESPONDENTS, IS THE LACK OF HEALTH CARE

ALSO, THE TOP RANKING POSSIBLE POLICY AND ADVOCACY INTERVENTION TO FOCUS THE COALITION ON, AS REPORTED BY RESPONDENTS, IS ACCESS TO HEALTH CARE

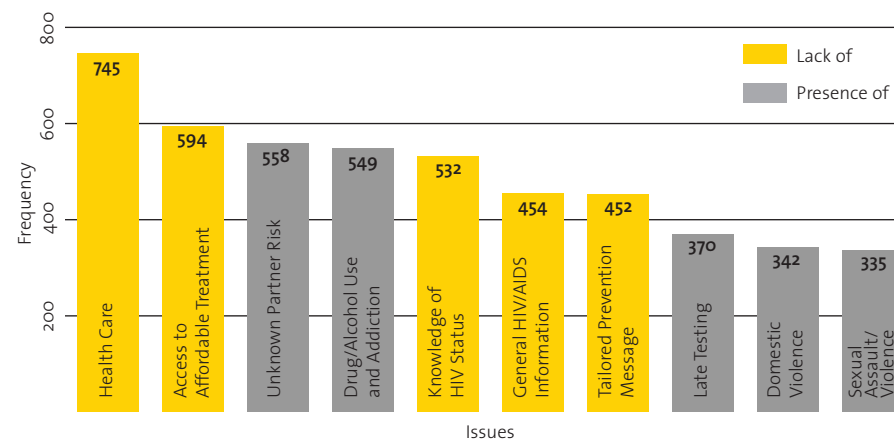
Results

When compared to their white female counterparts, it has been reported that African American women are 25 times more likely to be diagnosed with AIDS (CDC, 2002). Through the years, the gap in HIV infection rates among African American women in comparison to other women in the United States continues to widen. Given the structural issues related to the disparate health conditions of African American women, it was not surprising to find that the participants included in the study chose more structural rather than individual factors currently affecting African American women at risk of or living with HIV/AIDS. According to the overall sampled respondents (Graph 1), the top

three issues facing African American women and their family at risk of and living with AIDS, were (1) lack of health care, (2) lack of affordable treatment and the (3) presence of unknown partner risk.

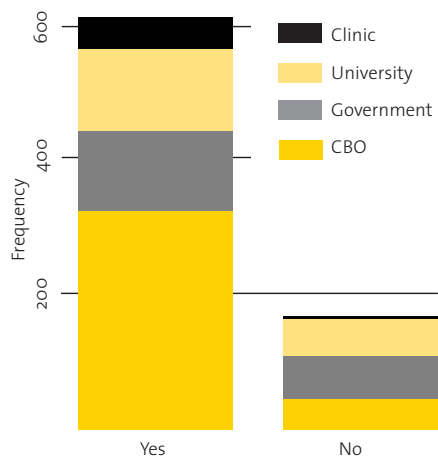
Respondents representing government agencies and colleges/universities had the same top three ranking of issues as the overall general results, (1) lack of health care, (2) lack of access to affordable treat-

Graph 1: Overall Top Ranking Issues Among African American Women



ment and (3) presence of unknown partner risk (Table 2). However, except for (1) lack of health care, organizations based in the community, such as CBOs and Clinics ranked

Graph 2: Willingness to Build a Coalition, Split by Organization Type



(2) presence of drug/alcohol use and addiction and (3) lack of knowledge HIV status as the top three issues affecting African American women and their families at risk of or living with AIDS (Table 2). Generalizing across each of the four organization types, CBOs, clinics, government agencies and universities, the results show that organizations based in the community like clinic and CBOs may most often choose risk behaviors as top issues facing African American women, while large government/private organizations may often choose structural issues.

In general, the majority or 77.3% of the respondents were willing to build a coalition with other public health representatives to advocate on behalf of African American

women and their family at risk of and living with HIV/AIDS. Among those who responded that they would be willing to build a coalition (613 total), 327 were from CBOs, 118 from government agencies, 121 from universities, and 47 from clinics (Graph 2). Graph 2 also depicts the breakdown, by count, of those who responded that they would not be willing to build a coalition (170 total). CBOs contributed to the highest count in each response due to the fact that the majority of respondents were from the CBOs (373 total). Conversely, clinics contributed the least proportionally to each category since there were the least number in that organization type (52 total). In Graph 3, when each organization type was broken

Table 2: Top Issues Facing African American Women

	CBO RANKING	CLINIC RANKING	GOVERNMENT RANKING	UNIVERSITY RANKING
1	Lack of Health Care (269)*	Lack of Health Care (52)	Lack of Health Care (160)	Lack of Health Care (145)
2	Presence of Drug/Alcohol Use and Addiction (240)	Presence of Drug/Alcohol Use and Addiction (39)	Lack of Access to Affordable Treatment (130)	Lack of Access to Affordable Treatment (133)
3	Lack of Knowledge of HIV Status (215)	Lack of Knowledge of HIV Status (37)	Presence of Unknown Partner Risk (125)	Presence of Unknown Partner Risk (108)
4	Lack of General HIV/AIDS Info (199)	Presence of Unknown Partner Risk (33)	Lack of Knowledge of HIV Status (110)	Lack of Tailored Prevention Message (91)
5	Presence of Unknown Partner Risk (195)	Lack of General HIV/AIDS Info (32)	Presence of Drug/Alcohol Use and Addiction (98)	Presence of Drug/Alcohol Use and Addiction (86)
6	Lack of Access to Affordable Treatment (188)	Lack of Access to Affordable Treatment (30)	Lack of Tailored Prevention Message (87)	Lack of Knowledge of HIV Status (81)
7	Lack of Tailored Prevention Message (178)	Lack of Tailored Prevention Message (28)	Lack of General HIV/AIDS Info (75)	Lack of General HIV/AIDS Info (74)
8	Presence of Late Testing (141)	Presence of Sexual Assault/Violence (27)	Presence of Late Testing (75)	Presence of Late Testing (66)
9	Presence of Sexual Assault/Violence (133)	Presence of Late Testing (26)	Presence of Domestic Violence (68)	Presence of Domestic Violence (66)
10	Presence of Domestic Violence (110)	Presence of Domestic Violence (25)	Presence of Sexual Assault/Violence (60)	Presence of Sexual Assault/Violence (65)

* Numbers in parentheses represent the total number of respondent that selected that particular issue

down individually, it became clear that CBOs and clinics were most supportive of building a coalition (with 88% and 90% willing to build, respectively). Government agencies and universities were both slightly

lower, though still majority, at 66% and 68% respectively.

Respondents were asked through an open-ended question why they would or would not be willing to build a coalition. Of the overall sam-

ple willing to build a coalition, 26.7% agreed primarily because they recognized a general need to attend to the health factors that plague African American women and the African American community. The participants' secondary motivation (20.9%) to join the coalition included providing a holistic, collaborative and interconnected approach to African American women's health. Other public health professionals (6.9%) wanted to be a part of the coalition because they were personally committed to reducing African American women's risk for HIV, confirmed that it was the mission of their organization to work with women of color or referred specific individuals within their organization whose expertise included African

American women and AIDS. According to 4.5% of the respondents, African American women often forget to take care of themselves or are provided limited health resources. Others respondents believed that the coalition can provide better services in the community and in public policy because the coalition has the ability to strengthen political and social voices to affect federal policy change.

The majority, 34.6% of public health professionals uninterested in building said the coalition's primary mission was outside of the scope, area and focus of their organization and professional career. Lack of time was a barrier common to 17.8% of the respondents who were not willing to build a coalition.

Graph 3: Willingness to Build a Coalition, According to Each Organization Type

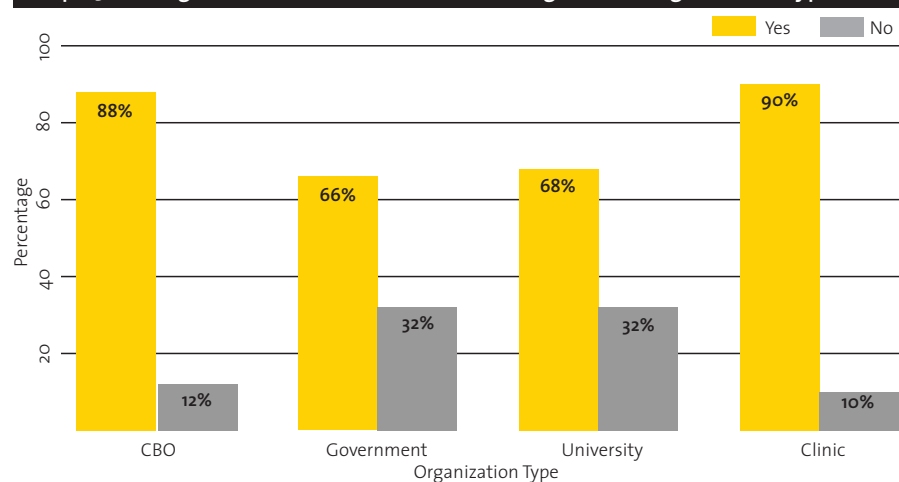
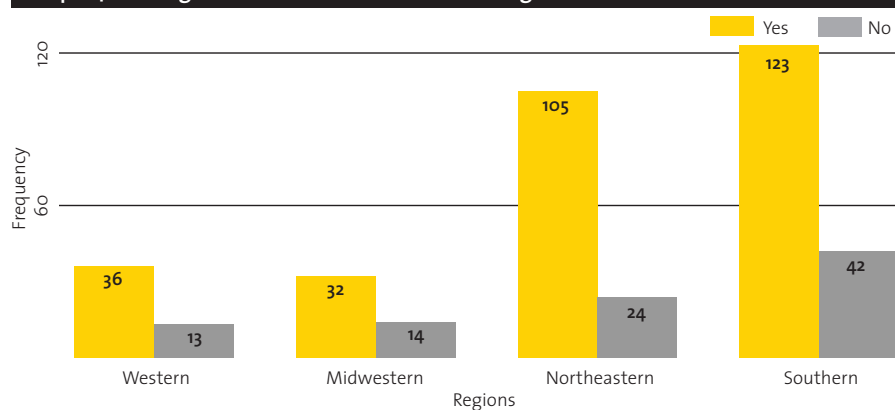


Table 3: Top Reasons for Willingness to Build a Coalition

Reason	Percent
Need in community	26.6%
Will provide holistic, collaborative and interconnected approach to African American women's health	20.9%
Personally or Organization committed to reducing African American women at risk for HIV	6.9%
African American women forget to take care of themselves	4.5%

Graph 4: Willingness to Build a Coalition and Regional Location



The regional location of the participants' organizations did not affect the participants' decision to assist in building a coalition to attend to African American women's health issues. Whether the participants'

organizations were located in the Western, Southern, Northeastern, or Western region, the majority willingly agreed to assist in building the coalition (Graph 4). However, given that the conferences took place in

the Southern and Northeastern regions of the United States it is not surprising to find that most of the representatives responding affirmatively were from southern and north-eastern regions.

Given that the participants selected lack of health care, lack of access to affordable treatment, and presence of unknown partner risk as the top three issues facing African America women; it is not surprising to find that the participants selected relevant policy focus to remedy these issues. When asked choose from a list of possible policy and advocacy intervention to focus the coalition, the respondents selected (1) access to health care, (2) prevention messages and (3) access to affordable treatment as the top

Graph 5: Areas Where Advocacy Should Focus, Overall Ranking

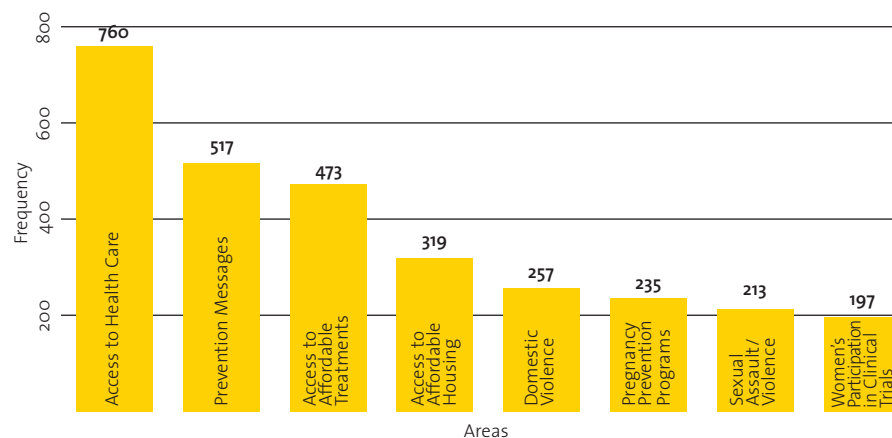


Table 4: Areas Where Advocacy Should Focus, by Each Organization Type

	CBO RANKING	CLINIC RANKING	GOVERNMENT RANKING	UNIVERSITY RANKING
1	Access to health care (266)*	Access to health care (160)	Access to health care (161)	Access to health care (48)
2	Prevention messages (193)	Prevention messages (105)	Prevention messages (103)	Prevention messages (28)
3	Access to affordable housing (150)	Access to affordable treatments (105)	Access to affordable treatments (103)	Access to affordable treatments (26)
4	Women's participation in Clinical trials (150)	Access to affordable housing (62)	Access to affordable housing (49)	Access to affordable housing (20)
5	Access to affordable treatments (101)	Pregnancy Prevention programs (49)	Pregnancy Prevention programs (46)	Domestic violence (20)
6	Sexual assault/violence (89)	Domestic violence (46)	Domestic violence (44)	Sexual assault/violence (16)
7	Domestic violence (88)	Sexual assault/violence (41)	Sexual assault/violence (37)	Women's participation in Clinical trials (15)
8	Pregnancy Prevention programs (78)	Women's participation in Clinical trials (36)	Women's participation in Clinical trials (29)	Pregnancy Prevention programs (12)

* Numbers in parentheses represent the total number of respondent that selected that particular issue

77.3%

THE PERCENTAGE OF RESPONDENTS
THAT WERE WILLING TO BUILD A COALITION

three areas that a coalition of representatives should focus their advocacy for African American women (Graph 5). Similarly, representatives from government agencies, universities and clinic agreed that access to health care, prevention messages and accesses to affordable treatment should be the top three policy focus. Although representatives from CBOs agreed with the top two policies focus, they believe that the third policy focus should be access to affordable housing (Table 4).

The majority, 96.7% participants believed that the coalition would provide effective advocacy for addressing public policy issues facing African American women and their families at risk of and living with HIV/AIDS. 46.3% believed the

coalition would provide effective advocacy, a collective voice to be heard and a means to empower the community. Other participants explain that the coalition would be effective because it would address women's health concerns, reduce risk of HIV among African American women and provide overall better services. Although most of the participants of this study believed that the coalition could empower and better serve African American women and their families at risk of and living with AIDS, 5.4% were a bit cautious. They explained that depending on commitment of all the agencies involved, the coalition's dynamics and efficiency and its cultural appropriateness, the coalition could provide effective advocacy to

address public policy issues facing African American women, their families and their communities.

96.7%

THE PERCENTAGE OF RESPONDENTS
THAT BELIEVED THE COALITION
WOULD PROVIDE EFFECTIVE ADVOCACY
FOR ADDRESSING PUBLIC POLICY ISSUES
FACING AFRICAN AMERICAN WOMEN AND THEIR
FAMILIES AT RISK OF AND LIVING WITH HIV/AIDS

Conclusion

Given the large marginalization of African American women's health issues, it is critical that today's primary influencers in women's health fields come together to prioritize and holistically address women health needs. Although public health professionals and government officials have many challenges ahead, the results of this study show that many physicians, policy advocates, community workers and other public health servers are willing to join together to collectively attend to African American women's health issues. The participants included in this study also believe that the a lack of health care is a major issue facing African American women and their families at risk of and living with HIV/AIDS.

Providing access to health care was also selected as the primary area to focus advocacy energies.

As there are no national coordination and few effective national initiatives that have managed to turn the tide for women's health, CEG seeks to coordinate a national system of women of color leaders, CBOs, capacity building assistance (CBA) providers, local and state health departments to develop a HIV/AIDS care, education, prevention and treatment needs.

26.7%

THE PERCENTAGE OF RESPONDENTS
THAT RECOGNIZED A GENERAL NEED TO
ATTEND TO THE HEALTH FACTORS THAT PLAGUE
AFRICAN AMERICAN WOMEN AND THEIR
COMMUNITIES AND WANTED TO WORK
TOWARD CHANGE

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17.8%

THE PERCENTAGE OF RESPONDENTS
WHO CITED LACK OF TIME AS A MAJOR
BARRIER TO JOINING A COALITION

Survey Instrument

**Waiting on Survey PDF to
finish pages 23 and 24.**

