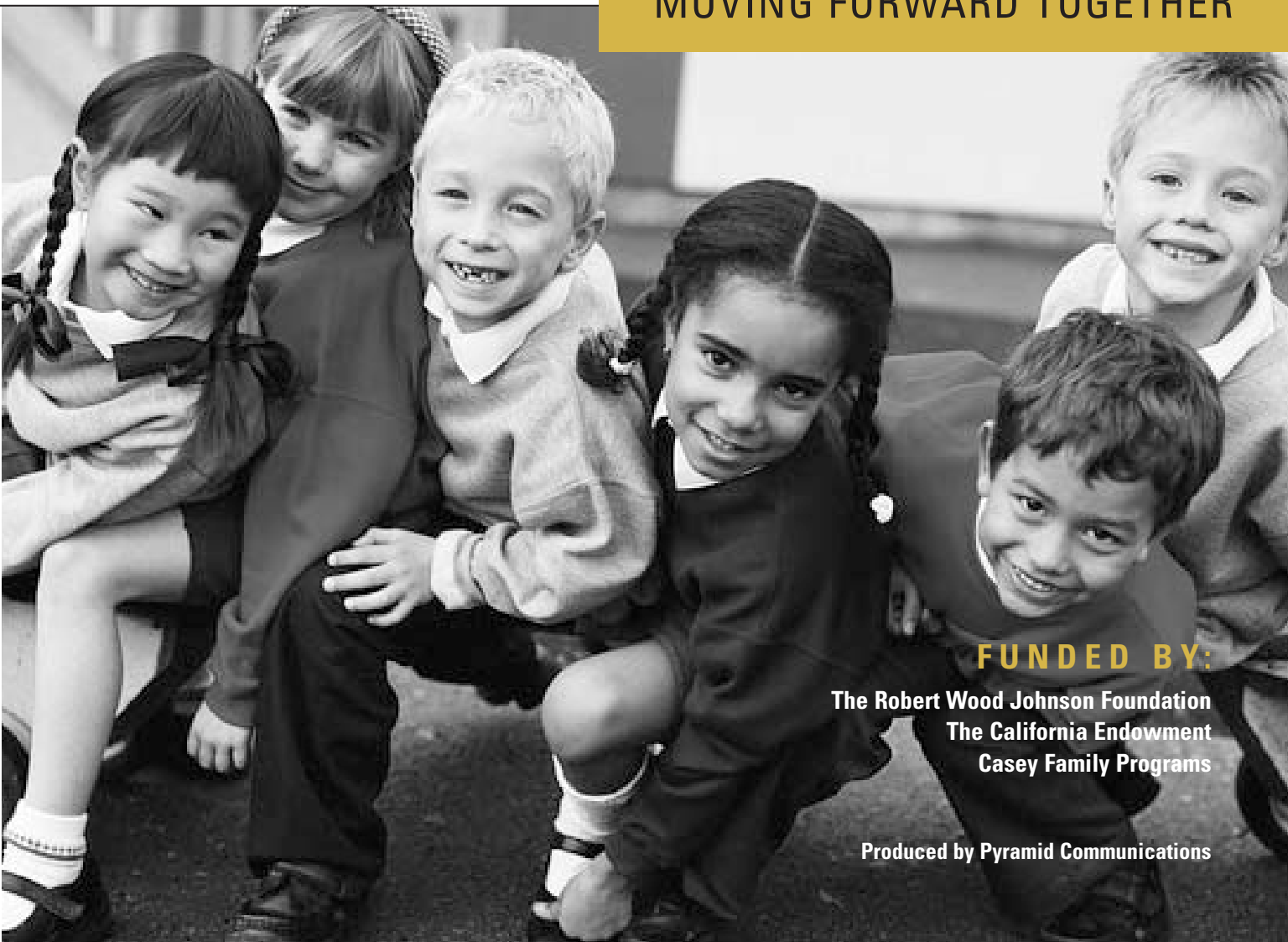


# EQUAL RIGHTS TO HEALTH

MOVING FORWARD TOGETHER



**FUNDED BY:**

The Robert Wood Johnson Foundation  
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*“In 1990, two New York doctors found that so many poor African-Americans in Harlem were dying young from heart disease, cancer and cirrhosis of the liver that men there were less likely to reach age 65 than men in Bangladesh.”*

—Helen Epstein, *The New York Times Magazine*, October 12, 2003

*“Many people believe that dealing with overweight and obesity is a personal responsibility. To some degree they’re right, but it is also a community responsibility. ... There is much that we can and should do together.”*

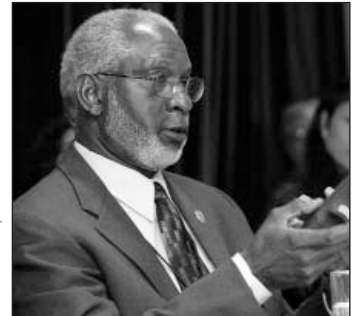
—David Satcher, M.D., Ph.D.

Interim President, Morehouse School of Medicine

Former Surgeon General of the United States

*Call to Action to Prevent and Decrease Overweight and Obesity*, 2001

David Satcher, Morehouse School of Medicine



## INTRODUCTION

The alarming rise of childhood obesity rates has some observers predicting that today’s children may be the first generation of Americans whose life expectancy will be *shorter* than that of their parents. According to the Centers for Disease Control and Prevention (CDC), the number of overweight kids in the United States has nearly doubled since 1980, and the number of overweight adolescents has nearly tripled. Already, kids are being diagnosed with conditions previously seen only in adults, such as type 2 diabetes.

African American, Latino and Native American children, particularly those in low-income communities, experience higher rates of obesity and greater disparities in health care than other children. Many of their families live in neighborhoods that don’t offer safe places for them to be physically active or stores that sell affordable, healthy foods. Many of these families lack health insurance and don’t have a personal physician. The double whammy of obesity-related health problems and disparities in health care threatens to create a public health disaster for America’s low-income minority populations.

To learn more about combating obesity among low-income racial and ethnic minority children, the Robert Wood Johnson Foundation (RWJF) collaborated with The California Endowment, Morehouse School of Medicine and Casey Family Programs to convene 55 experts at the *Equal Rights to Health* roundtable at Morehouse School of Medicine in December 2003. The outcome was a set of suggested action items, which are contained in this report.



Risa Lavizzo-Mourey, RWJF

*“We must halt the epidemic of childhood obesity among children in high-risk, unequally treated populations... We all need to seek partners on many fronts—parents, schools, community and faith-based organizations, researchers, health care providers, public health professionals, policy-makers and businesses. Together, we can halt the alarming trends in our nation.”*

—Risa Lavizzo-Mourey, M.D., M.B.A.  
President and CEO, The Robert Wood Johnson Foundation  
*Equal Rights to Health, 2003*

The collaboration needed to accomplish the action items identified at the roundtable is clearly possible, as the roundtable demonstrated. Working together to leverage resources and share information, we can reduce duplication of efforts and take the next step toward the goal of equal rights to health for all Americans.

*“If we don’t work collaboratively, we’re not likely to get meaningful social change on this or really any other important issue.”*

—Marion Standish, J.D.  
Program Director, The California Endowment  
*Equal Rights to Health, 2003*

## SUMMARY OF RECOMMENDED ACTIONS

### **Promote Stronger Community-Based Research Partnerships that are Culturally Sensitive**

- Elevate the importance of community service and community-based research within the academic reward system.
- Fund grants to encourage minority students to become researchers.
- Create alternative peer-reviewed journal guidelines in this field.

### **Clarify Program Evaluation Needs and Standardize Approaches**

- Agree on a definition of “success.”
- Create or agree on standardized evaluation tools.

### **Provide Technical Assistance to Enhance Community Programs**

- Provide training for community members and community-based organizations in grantsmanship and program evaluation.
- Strategize with the community to increase media attention to program activities, either in classes or by disseminating standardized media materials.
- Provide communications resources to help researchers make their findings accessible to lay audiences.

### **Learn From and Work with the Corporate Community**

- Employ professionally developed, consumer-targeted strategies to market physical activity and healthy eating programs.
- Partner with businesses to share and/or support efforts.
- Consider the value of litigation to achieve policy change.

### **Create a Central Information Infrastructure**

- Create a Web site where people in the field can easily access consolidated information.
- Convene regular conferences for people in the field to meet and discuss their challenges and progress.
- Create a new journal for culturally appropriate work.
- Create a dissemination model.

### **Revise Funding Policies to Support These Recommendations**

- Consider mechanisms for making grants to both community-based organizations and academic researchers.
- Require evidence of community involvement in grant applications.
- Fund replication of successful programs.
- Fund environmental change programs that increase community infrastructure and build capacity.

## 1

## PROMOTE STRONGER COMMUNITY-BASED RESEARCH PARTNERSHIPS THAT ARE CULTURALLY SENSITIVE

Recommendations for action identified at the Equal Rights to Health roundtable are detailed on the following pages. These recommendations form an agenda for the academic and philanthropic communities to undertake in support of reducing childhood obesity in low-income racial and ethnic minority communities. The basic premise of the recommendations is that relevant approaches should be framed from culturally appropriate perspectives, where cultural appropriateness is best achieved through maximum community involvement in program design, implementation and evaluation.

Participants at the roundtable identified the action items, which do not necessarily represent the viewpoint of any sponsors. It was beyond the scope of the roundtable to reach consensus on the specific details necessary to meet the recommendations. Interested philanthropies and academic institutions need to come together to figure out how to address and achieve each recommendation. Action items are organized in six broad categories. This report was reviewed by a group of eight experts who have provided feedback on its development. A full list of these experts can be found in the Acknowledgements.

During discussions at the roundtable, frequent references were made to an element of tension between community members and researchers who attempt to implement community programs. The tension stems from the researchers' intense focus on evaluation, documentation and publication. Community members often feel they are subjects of the research rather than real people with real needs. Even those researchers who would prefer to focus on program services rather than publication feel they cannot do so because their value in the academic community is measured by peer-reviewed publications.

## ELEVATE THE IMPORTANCE OF COMMUNITY SERVICE AND COMMUNITY-BASED RESEARCH WITHIN THE ACADEMIC REWARD SYSTEM

Universities and academic health centers appear to increasingly recognize their responsibility to contribute to the quality of life in their surrounding communities. In addition, research funding agencies recognize the importance of partnering with communities in developing and implementing research that will help solve priority health problems. However, the development of reward mechanisms for faculty who engage in service or research activities with this orientation has lagged. Research programs that focus on or involve community are still very much undervalued and not rewarded in the academic environment, although the service-related portion of the work may be highly valued in the community. For example, incentives such as academic tenure and/or continued funding are often based on a researcher's ability to publish. This creates a situation in which a researcher may focus on obtaining publishable results in ways that can inadvertently cause the research to come across as intrusive or culturally inappropriate, thereby contributing to tension with the community. Or, the researchers who are more responsive to the community in their research do not succeed as researchers and may have to leave their university positions.

*“You’re either a researcher, or you’re out there in the community advocating and working. You can try to merge the two, but it’s difficult because working in the community and gaining the trust of the community means that you have to do a lot of face time. It’s not just going in there. It means dinners. It means community boards. It means so many things that aren’t valued in the academic setting.”*

—Ivan Lugo, D.M.D., M.B.A.  
Associate Dean, Temple University School of Dentistry  
*Equal Rights to Health, 2003*

*“An important strategy is to expose minority students at an early stage in their career to community-based research and issues, to get them engaged and interested in public health. The earlier we start, the more successful we’re going to be.”*

—William Dietz, M.D., Ph.D.  
Director, Division of Nutrition and Physical Activity  
Centers for Disease Control and Prevention  
*Equal Rights to Health, 2003*

Creating other incentives (e.g., research funders reinforcing the importance of community involvement by requiring researchers applying for grants to demonstrate a community partnership), or finding other ways to put pressure on institutions to place a higher value on service-related work during consideration for tenure and promotion, would shift this bias. This will require educating academic leaders as to the scientific value of community-based research and to the criteria of merit that can be appropriately applied to such research. Academic institutions will improve their relationships in the community by promoting community service, which enhances both the research and research training missions of universities. Recognition for their work would encourage faculty who implement service-related programs that are welcomed by the community to continue these activities.

## FUND GRANTS TO ENCOURAGE MINORITY STUDENTS TO BECOME RESEARCHERS

Despite the fact that ethnic and minority communities relate and respond better to those who share their background, there are not enough researchers of the same race or ethnicity of the target communities. Engaging and supporting minority students in pursuing research on how to promote physical activity and healthy eating for children will improve the balance and efficacy of work done in these communities.

*“We need to identify and nurture individuals of color so that they develop the research skills and achieve the professional benchmarks that are expected in order to contribute to the research that is being done.”*

—Terry Bazzarre, Ph.D., F.A.C.S.M.  
Senior Program Officer, The Robert Wood Johnson Foundation  
*Equal Rights to Health, 2003*

## CREATE ALTERNATIVE PEER-REVIEWED JOURNAL GUIDELINES IN THIS FIELD

Many community-based research intervention programs are advancing the field, but results are not published because of strict academic guidelines. Because service and activity are often the focus, as opposed to evaluation, these otherwise successful programs are not published or recognized, and few people learn about them. Adding alternative sections to peer-reviewed journals, with separate guidelines that community-based programs can meet, will make information available about programs evaluated with less academic rigor, but that nonetheless produce important knowledge. The guidelines for reporting “Community Case Studies” in the CDC Journal *“Preventing Chronic Diseases”* are an example.

# 2 . CLARIFY PROGRAM EVALUATION NEEDS AND STANDARDIZE APPROACHES

Mary Muivihill, San Diego State University



The lack of clarity as to what constitutes an appropriate evaluation of a community-based program and the diversity of instruments used or outcomes assessed when programs are evaluated essentially means that every physical activity and healthy eating program evaluates itself differently, if it is evaluated at all. Frustration around this topic was aired at the roundtable. There are no widely recognized evaluation standards, so programs cannot be compared effectively to fully

understand what works and what doesn't. The lack of these standards also makes it difficult for community-based programs to perform the evaluations needed to secure initial or continued funding. Creating evaluation standards is a step toward consolidating needed information and providing tools to the community. More programs can then develop organically from within communities.

## AGREE ON A DEFINITION OF "SUCCESS"

A program that aims to promote physical activity and healthy eating should not have its success based solely on changes in participants' body mass index (BMI) scores<sup>1</sup>. Such a focus targets only the change in weight rather than a healthy improvement in lifestyle. Many low-income ethnic and racial minority communities see greater value in other measures of lifestyle change (e.g., "total health" or "an expanded view of health"). It may be necessary to address physical, mental, social, spiritual and socioeconomic factors to bring about real changes. Including indicators of lifestyle change in a standardized definition of "success" will help shift the focus to realistic, sustainable goals on which both community stakeholders and academics can agree. Developing a common definition of success and disseminating it widely will help clarify which evaluation elements are needed in programs to reduce obesity in low-income ethnic and minority communities.

*"This tension between research and community service is fundamentally a question of evidence. What is the evidence? If you work with faith communities, you'll find they have a whole different set of what they believe is evidence versus investigators. We need proximal measures of success that are not immediate changes in BMI, that the federal agencies and foundations see as legitimate outcomes."*

—Stephen Thomas, Ph.D.  
Director, Center for Minority Health, University of Pittsburgh  
*Equal Rights to Health*, 2003

<sup>1</sup> Body Mass Index charts for boys and girls can be found at <http://www.keepkidshealthy.com/growthcharts/index.html>

## CREATE OR AGREE ON STANDARDIZED EVALUATION TOOLS

Creating culturally appropriate evaluation tools that can be disseminated to the community will enable communities to advocate for and evaluate their own physical activity and healthy eating programs. Such tools can enhance program implementation, as well as create an environment that will become a cyclical component of program sustainability. In addition, standardized evaluation tools can facilitate comparisons between programs and the identification of best practices.

- **“Total health”**—Racial and ethnic minority communities tend to value measures of their total health and quality of life more than measurements of their BMI. The balance of the two measurements needs to be resolved, so community members feel like they are receiving useful feedback. Developing a standard tool that measures total health in addition to BMI would be a significant contribution.
- **Short- and long-term progress**—Providing tools that help programs create short-term milestones will help participants reach their long-term goals. A tool that allows participants to measure their progress toward their short-term goals will help them maintain their focus and motivate them to continue striving to achieve their long-term goals.
- **Cultural sensitivity**—A tool to measure the cultural sensitivity of a program would aid philanthropies in evaluating how well a program is adapted to its target community.
- **Program sustainability**—A tool to help identify and measure sustainability will help communities build programs that persist longer and help more people. It also will provide philanthropies with important information to guide funding decisions. Encouraging sustainability will increase the prevalence of programs that benefit the community in the long run.

*"It would be great if you could show schools that physical education and good nutrition increase performance on the standardized exam, since that is what they are most worried about."*

— David Satcher, M.D., Ph.D.  
 Interim President, Morehouse School of Medicine  
 Former Surgeon General of the United States  
*Equal Rights to Health, 2003*

Standardizing evaluation approaches does not preclude adaptations to make tools sensitive to a given community. The intent is to strive for instruments and outcome measures that reflect relevant issues to both researchers and communities, and to permit meaningful comparisons of outcomes across different programs.

# 3 ■ PROVIDE TECHNICAL ASSISTANCE TO ENHANCE COMMUNITY PROGRAMS

At the roundtable, many people noted that there are numerous physical activity and healthy eating programs *already* on the right path, and what they need is a little extra leverage to help them reach full potential. Oftentimes, funding structures work in such a way that, by the time a program is finally accepted in a community, funding runs out and the program dissolves. The roundtable consensus was that there's no point in reinventing the wheel when an existing program is already halfway there.

## PROVIDE TRAINING FOR COMMUNITY MEMBERS AND COMMUNITY-BASED ORGANIZATIONS IN GRANTSMANSHIP AND PROGRAM EVALUATION

Community members and organizations often fail to gain funding, or they lose funding, because they are unable to clearly demonstrate a need for the program or demonstrate its efficacy. Because the most sustainable programs are those that originate from within the community, offering easy-to-access and affordable “how-to” classes on grant writing, asset mapping, program design, implementation and evaluation to community members would encourage self-starters.

Philanthropies and/or researchers could provide training to communities as part of the grantmaking process. This kind of relationship would enable the community to design, implement and evaluate a successful, sustainable program without depending entirely on academic researchers to verify results and monitor progress.

## STRATEGIZE WITH THE COMMUNITY TO INCREASE MEDIA ATTENTION TO PROGRAM ACTIVITIES, EITHER IN CLASSES OR BY DISSEMINATING STANDARDIZED MEDIA MATERIALS

Community-based programs often have a difficult time getting media coverage. They may lack the tools and knowledge required to get such coverage. Communications materials, tools and media outreach training will help community programs get media attention that can boost involvement and funding.

*“I was living in one reservation community at the time PBS aired their Diabetes Project special. What was really interesting is how it offered a tremendous amount of cultural pride to the community. I think it probably encouraged more involvement because everyone was thinking, ‘The whole nation thinks we’re doing this, so we better get involved!’”*

—Nicolette Teufel-Shone, Ph.D.  
Associate Professor, Mel and Enid Zuckerman College of Public Health  
University of Arizona  
*Equal Rights to Health*, 2003

## PROVIDE COMMUNICATIONS RESOURCES TO HELP RESEARCHERS MAKE THEIR FINDINGS ACCESSIBLE TO LAY AUDIENCES

Many researchers are not adept at making their findings accessible or understandable to the general public. While their research articles might make sense in the academic world, the work does not reach or make an impact upon the general public or communities where it is often needed most. Helping researchers “translate” their findings for the general public and connect with appropriate dissemination vehicles will make their work more valuable and appreciated outside of the academic world.



Nicolette Teufel-Shone, University of Arizona

# 4 ■ LEARN FROM AND WORK WITH THE CORPORATE COMMUNITY

It may be necessary to address corporate contributions to the problem if the childhood obesity epidemic is to be reversed. Corporations use a variety of strategies to increase their profits. It was obvious to many at the roundtable that advertising and media heavily influence youth culture. Companies understand the power of advertising and are masters of marketing to youth. Corporations form partnerships for product placements and co-branding to further their reach and they resort to litigation when it is necessary to protect their interests.

## EMPLOY PROFESSIONALLY DEVELOPED, CONSUMER-TARGETED STRATEGIES TO MARKET PHYSICAL ACTIVITY AND HEALTHY EATING PROGRAMS

Professional market research and advertising are needed if we are to compete realistically for cultural relevance. Helping community leaders of physical activity and healthy eating programs to acquire advertising savvy will boost interest within the community and among youth.

*“We need to compete [against industry] very aggressively and very hard and we can do it in ways that cost less money because we have better access to the community than they do, and that’s the card we’re not playing right now.”*

—Ivan Juzang

Founder and President, Motivational Education Entertainment Productions, Inc.

*Equal Rights to Health, 2003*

## PARTNER WITH BUSINESSES TO SHARE AND/OR SUPPORT EFFORTS

Companies (fast food restaurant chains, athletic equipment manufacturers and stores, drugstore chains, etc.) potentially can be useful partners by funding programs, sponsoring community efforts or advertising programs. They receive positive publicity by involving themselves in physical activity and healthy eating projects, but it must be acknowledged that some companies might view a partnership as a way to “buy” credibility with the community. Philanthropies can explore opportunities to collaborate with them, but they should also exercise caution since corporate partnerships can sometimes decrease the credibility of the participating philanthropy.

Robert Wilkins, YMCA of the East Bay



## CONSIDER THE VALUE OF LITIGATION TO ACHIEVE POLICY CHANGE

Some participants at the roundtable recommended taking legal action against companies that market to low-income communities, minorities and children, just as in the fight against tobacco companies. Proceeds from successful litigation could then be used for programs in those same communities that were taken advantage of. Participants noted that litigation draws attention to an issue.



Shiriki Kumanyika, University of Pennsylvania  
School of Medicine

# 5 ■ CREATE A CENTRAL INFORMATION INFRASTRUCTURE

As people talked to each other at the roundtable, it became apparent that sharing information was proving very useful. There is a lot of existing information about this field, but much of it is hidden deep within Web sites or textbooks, or is simply unpublished, making the information virtually inaccessible. Consolidating knowledge in one place will help identify gaps in knowledge and reduce the risk of duplicating work.

## CREATE A WEB SITE WHERE PEOPLE IN THE FIELD CAN EASILY ACCESS CONSOLIDATED INFORMATION

In order to avoid duplicating work that has already been completed, develop a Web site with consolidated information to reduce wasted time.

*“Right now, sitting at NIH and CDC and many of the agencies that fund these research studies, they have all the tools sitting there. You pay for them with your tax dollars, but I’ve got to go eight clicks to find it. And why isn’t that franchised, why isn’t that licensed? Get those materials more accessible, not buried on some agency’s Web site.”*

—Stephen Thomas, Ph.D.  
Director, Center for Minority Health, University of Pittsburgh  
*Equal Rights to Health*, 2003

## CONVENE REGULAR CONFERENCES FOR PEOPLE IN THE FIELD TO MEET AND DISCUSS THEIR CHALLENGES AND PROGRESS

As the roundtable demonstrated, getting people in the field engaged leads to collaboration, inspiration, consolidation of information and, ultimately, progress. Holding regular conferences so colleagues can meet and discuss the challenges they're facing and the progress they're making will fuel the momentum of their work toward increasing physical activity and healthy eating among youth in low-income, racial and ethnic minority populations.

## CREATE A NEW JOURNAL FOR CULTURALLY APPROPRIATE WORK

While some thought it would be a great deal of work, others at the roundtable believed that founding a new journal in this field that is accessible to community members, as well as funders, would raise awareness and interest in the issue and help spread best practices. The journal would publish articles and case studies that might not otherwise pass the strict academic guidelines of other journals, and the content would be written in such a way that it would make sense to a broad audience.

## CREATE A DISSEMINATION MODEL

If useful tools and documents are not shared, their value is wasted. Effective dissemination to community-based organizations, philanthropies, policy leaders and others is essential to making a real difference. An effective dissemination model is just as critical as producing necessary programs and it is currently missing from the landscape.

Robert Ross, The California Endowment



# 6 ■ REVISE FUNDING POLICIES TO SUPPORT THESE RECOMMENDATIONS

Some of the issues that arise between community members and researchers result from the very funding processes that enable such relationships.

## CONSIDER MECHANISMS FOR MAKING GRANTS TO BOTH COMMUNITY-BASED ORGANIZATIONS AND ACADEMIC RESEARCHERS

Currently, many programs in the field receive their funding through grants given to academic researchers, creating tension with communities who feel used as “subjects.” It was suggested at the roundtable that current funding models be changed so that community programs are in control of funds and can choose with whom they contract for research. Others argued that this model would not alleviate tensions but just change their focus. Meanwhile, researchers would no longer have incentives to do community work if they couldn’t have the grant under their name. Some researchers discussed options in which the community and the research institution each could be responsible for half of the grant, so both parties would be equally accountable. It is important to consider the options and use funding to bridge differences and build stronger partnerships.

## REQUIRE EVIDENCE OF COMMUNITY INVOLVEMENT IN GRANT APPLICATIONS

By providing meaningful letters of support from partners in the community, grant applicants can better show their commitment and relationship with the target community. Demonstrating a genuine relationship with the community will ensure that the most critical element of being culturally appropriate—strong community involvement—is in place.

## FUND REPLICATION OF SUCCESSFUL PROGRAMS

Replicating effective programs and processes is easier and more cost-effective than repeatedly creating new ones. While each community may develop a program to fit its unique characteristics, a certain degree of “franchising” methods and processes of effective programs will make it easier for communities and organizations to succeed. Selecting promising programs and creating an attractive package that can be replicated around the country for evaluation in various locations will decrease the duplication and reinvention that currently takes place.

*“We keep reinventing the wheel over and over, and there are programs like the ones we’ve discussed here this morning that are not only successful programs but that are really touching the lives of people. Sometimes, the successful programs that die when the funding dies have the potential not only to be replicated but also have the potential to become better programs.”*

—Aracely Rosales  
President, Plain Language and Culture  
*Equal Rights to Health*, 2003

## FUND ENVIRONMENTAL CHANGE PROGRAMS THAT INCREASE COMMUNITY INFRASTRUCTURE AND BUILD CAPACITY

The best program cannot succeed in a community without resources. Recognize that program sustainability takes time in communities with few resources and little community support. Be realistic about the period in which sustainability is reasonable and understand that the programs that make the most impact do so by establishing roots in the community over several years.

*“The most frequent question that Tribal Council asks researchers from the outside is, ‘What’s going to happen when you leave?’ They aren’t into researchers coming in for four or five years, getting publishable results and then leaving the community once they have what they need. I think that’s a strong message that is coming out of this community. As a result, there is very little tolerance for someone coming in and saying they can get a lot of money for a great start. Unfortunately, American Indian communities have seen too many ‘great starts’ and not enough sustainability.”*

—Nicolette Teufel-Shone, Ph.D.  
Associate Professor, Mel and Enid Zuckerman College of Public Health  
University of Arizona  
*Equal Rights to Health*, 2003

# 7 ■ CONCLUSION

If the epidemic of obesity among low-income minority children is to be halted, action must be taken now. We cannot abandon the current generation while we search for antidotes that are more effective. If we don't act to reverse the alarming trend of childhood obesity, we are in danger of raising the first generation of American children who will live sicker and die younger than the generation before them. If we fail to bring this epidemic under control, we will pay a terrible human, health and fiscal price as far out into the future as we can imagine.

Philanthropies and academia should begin immediately to initiate these action items. Standardized evaluation tools, training for people to work directly in communities and revamped grant criteria could produce immediate gains in the field.



Debra Vinci, University of West Florida

Although some recommendations in this action agenda may take a little longer to implement, they should be undertaken now in order to make a difference in the near future. The need for this work is urgent. The health and well-being of American children depends on it.

# 8 ■ ACKNOWLEDGEMENTS

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Neighborhood Healthcare

## **Arnell Hinkle, M.P.H., R.D.**

California Adolescent Nutrition and Fitness  
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## **Jennie Joe, Ph.D., M.P.H.**

University of Arizona College of Medicine

## **Shiriki Kumanyika, Ph.D., M.P.H., R.D.**

University of Pennsylvania School of Medicine

## **Rebecca Mullis, Ph.D., R.D.**

University of Georgia College of Family and  
Consumer Sciences

## **Mary Mulvihill, Ph.D.**

San Diego State University

## **Nicolette Teufel-Shone, Ph.D.**

University of Arizona

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U.S. Centers for Disease Control and  
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**Shiriki Kumanyika, Ph.D., M.P.H., R.D.**  
University of Pennsylvania School of Medicine

**Debra Vinci, Dr.P.H., R.D.**  
University of West Florida (formerly of  
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Wake Forest University School of Medicine

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**Ivan Juzang**

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**Mary Ann Phillips, M.P.H.**

Georgia Health Policy Center

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