# THE CENTERS' FOR DISEASE CONTROL AND PREVENTION YOUTH MEDIA CAMPAIGN SUMMARY OF INTERVIEWS REGARDING KIDS WITH DISABILITIES

### **Background**

The Centers for Disease Control and Prevention's (CDC) Youth Media Campaign (YMC) was awarded \$125 million from Congress in 2001 to initiate a five-year effort to promote physical activity among children aged 9 to 13. The CDC has contracted with the best kids marketers, one national general market and four multicultural advertising agencies, to strategically market campaign messages through numerous touch points with "tweens" (children aged 9 to 13)—schools, television, radio, magazines, the internet, events, and partner organizations in communities. The Youth Media Campaign seeks to increase and maintain physical activity among tweens, through a multi-component campaign, with one overall campaign brand.

From late 2001 to March 2002, the campaign contractors conducted formative research to gain insight into the unique tween culture to develop a campaign brand. Then, the contractors went into a message development and testing phase for general market and for the African American, Asian American, American Indian, and Hispanic/Latino tween and parent audience segments. In an effort to learn how to more appropriately include kids with disabilities in subsequent concept and message testing and in future campaign messages and events, Westat, the YMC evaluation contractor, conducted semi-structured telephone interviews from July to August 2002 with ten individuals from two groups; those who represented organizations that promote physical activity for individuals with disabilities and those who have experience in developing messages for individuals with disabilities. For more specifics on the interview topics, please refer to the interview guide in Appendix A. Once interviews were completed, the Westat interviewer analyzed the data by reviewing interview notes and identifying common themes. The information that follows represents a synthesis of responses from interview respondents to various interview topics.

#### I. How can we include children with disabilities in the YMC activities and events?

The most important requirements for including children with disabilities in YMC are getting the right mix of possible activities and getting the message right in order to encourage them to participate. Key elements in this will be (1) treating them as "normal" participants rather than "special" participants, (2) making sure that the parents, advocates, and activists in each community are completely informed, (3) involving parents and (where possible) the children themselves in the local planning, along with community representatives that include advocates of the disabled, and (4) recognizing that, for the most part, these are children like any others and

When these interviews were conducted, the Campaign sought to increase tween involvement in positive activities, which included prosocial and physical activities. The Campaign has since refined its focus to promote physical activity.

will respond to the same basic message. Because one of the main problems for children with disabilities (and their parents) is the lack of information about what is actually available in their communities for them to do, the publicity campaign of YMC should, if it is comprehensive enough, make a valuable contribution to their continued involvement after the campaign is finished.

### What activities should be included?

Most of those interviewed (keeping in mind that most of them represent organizations related to sports activities for those with disabilities) expressed the opinion that the activities should be more sports-oriented than game-and-activity oriented. The preferable environment for their involvement is in real mainstream sports, not ones that are made up for them. Sports specifically mentioned by the respondents as being suitable for children with disabilities to participate in are track and field, basketball, swimming, skiing, cycling, table tennis, archery, soccer, weightlifting, volleyball, and tennis. Basketball and tennis are most often thought of as the wheelchair varieties, as is table tennis (with lowered tables) for most participants. Sports such as skiing, and cycling are thought of as "adaptive" sports, meaning that they will require special gear appropriate to the disability of the participants.

Of those who saw or had described for them the proposed activities, most felt that many of the activities and sports were appropriate, with the exception of Red Rover and Dodge Ball, which can leave players with lesser ability (or, of course, disability) unduly frustrated. There was some feeling that 11- and 12- year-olds might be too mature for some of the games, and that they would relate more to the sports, especially with the inclusion of some of the sports mentioned in the previous paragraph.

### Relevant characteristics of children with disabilities

The general problem of youth obesity and lack of fitness is exacerbated in kids with disabilities for a variety of reasons. They are discouraged from participating in sports, games, and activities because of their experiences in school and organizations, where they are made to feel "special" and where it is clear that their presence makes others uncomfortable. There is also a lack of information about possible areas of participation. Their parents are frequently too busy and frustrated to address their socialization and fitness needs. Parents frequently lack the resources to transport them to activities. One respondent researcher mentioned that, while some 25% of non-disabled youth are obese and sedentary in their habits, the percentage for those with disabilities is three times that. Youth with disabilities are most likely to resort to television, computers, and video games for their entertainment.

Potential **motivators** for participating in physical or prosocial activities are not much different for youth with disabilities from those with no disabilities. They should be reminded of the importance of exercise to their general health (probably even more important for those with disabilities) and should be encouraged to participate with others in both prosocial and sporting activities. They should be included in the population of participants, not made a separate

population, and the events should be adapted where necessary to provide a "level playing field" for competition. These children with disabilities need both physical and prosocial involvement even more than children with no physical disability, and generally they get less of it unless additional efforts are made.

**Preferences** of young people with disabilities are surprisingly like those of others the same age. They want to compete, once they discover that the opportunity exists. They like to compete with the non-disabled, when the circumstances (rules, conditions, etc.) can be altered to provide equal opportunity for success. They understand their disabilities better than most adults think, and can handle whatever happens if they think they have had a fair chance.

Children with disabilities obviously have **barriers and challenges** related to their disabilities, which of themselves reduce their range of opportunities. In addition, they have the stigma attached to being different, the burden of their experiences in school and in other social situations, often the lack of knowledge of what is available to them in their communities, and often the lack of means to participate (transportation, needed companions, etc.). This said, the respondents were in agreement that these children would overcome these barriers, and function like others of their age, if they get the chance to participate in something like the YMC activities.

The **kinds** of **potential benefits** of physical and prosocial involvement, in fitness and in self-confidence derived from social acceptance, will be essentially the same for these as for other young people. The difference is in **degree**. Because of their situation, youngsters with disabilities stand to reap much larger benefits from participation, and this makes the extra effort involved in making whatever provisions and adaptations that are required for their participation more than worthwhile.

## 2. How can we involve children with disabilities and their parents/guardians/families in the YMC messaging?

One area of agreement on this issue is that people with disabilities, including very young people, are a lot more like others the same age than most people realize. Disabled youngsters in the 9-13 age group are more likely than disabled adults to have been disabled for their entire lives (or most of them). Thus, having a disability is more "normal" for them than for many adults in similar circumstances, including some of the adults with disabilities that we have interviewed for this report. It is therefore important that these young people feel that being included in a program such as the YMC is logical and routine and not a "special" event. It will, however, be helpful to include such inducements as "success stories" of others like themselves, and to select sports, games, and other activities in which they feel that they can compete. There is a delicate balance required here, and involving them successfully will, in the opinion of those interviewed, require the involvement of disabled people, both adults and those of the target age group, in the final stages of the planning processes. This is true both for the activity planning and the planning of the messaging.

### How to portray children with disabilities

There was considerable agreement among those interviewed that the most important aspect of this is to use "people first" language instead of emphasizing the disability. For example, do not say "wheelchair-bound"; instead say "wheelchair user" or even better although a little cumbersome "person who uses a wheelchair." Among the more obvious examples are use of terms such as "visually impaired" and "hearing impaired" unless the persons described are totally blind or deaf. Another example is to describe those who are missing limbs as "prosthesis users" or "persons who use prostheses." The print media outlets identified in Appendix C contain other examples.

A second major point here is to use the most inclusive language possible, in which those with disabilities are seen as normal and not "special" (a word they all hate) and that including them is not portrayed as "an extra effort." Rather, they should be included in a seamless presentation that does not "make a big deal" out of their inclusion.

The media outlets listed in Appendix C are seen as appropriate sources for examples of the kind of language most suitable for portraying people with disabilities, and representatives of those media and publications may also be suitable for testing the messages once they are developed.

### Types and degrees of disability most easily portrayed

Young people with visible but not extraordinary or extreme disability would be most easily portrayed. If text is to be accompanied by pictures, then the visibility is important. Much of this will also depend on the types of sports and activities that are selected, and the extent to which the operators of the programs are willing to consider the use of adaptive gear in order to allow youngsters with disabilities to compete on an equal footing with those without disabilities.

### **Existing research?**

Special messaging for the disabled is an area in which, according to those interviewed, not much has been done. People who are involved in the field have evolved their own way of describing and discussing handicaps and people with handicaps, but have not classified it as research. None of the respondents, even those at the universities (who would certainly be in a good position to know, and who appear extremely knowledgeable in the general field) could suggest any useful formal research. Perhaps this YMC project can "plow new ground" in this area, as some of them suggested. The possibility of this might even attract some assistance from them, should they be asked.

### Getting representation for children with disabilities

The consensus on this is that the best way is to work through the advocacy organizations and organizations that actually work with youth with disabilities. The organizations represented in Appendix B are a good starting point. The seven Web sites described in Appendix D provide

additional detail as to sources of help in the various required ways, both nationally and in the states and cities where the YMC will be implemented.

### APPENDIX A: Discussion Guide for Stakeholder Interviews within Disability Organizations

### **Purpose:**

- To learn how to appropriately include kids with disabilities in the YMC messaging and events.
- To learn how to include kids with disabilities into YMC concept and message testing.

## Interview Guide (Note to interviewer: these are suggested topics for interviews. Interviews will vary from person to person, depending upon their professional expertise in working with individuals with disabilities).

- 1. What terminology should we use to speak about children with disabilities?
- 2. From your perspective, how do 9 to 13-year-old people with disabilities spend their time? Free time?
- 3. What are the motivators for physical and prosocial involvement with this population?
- 4. What are their preferences for physical and prosocial activity?
- 5. What are the barriers and challenges of disabled children, beyond the obvious?
- 6. What are the benefits of physical and prosocial activities, beyond the obvious?
- 7. How do we portray kids with disabilities partaking in prosocial and physical activities, being sensitive to their needs, wants, and constraints? What types of disabilities can be easily portrayed in campaign messaging (broadcast, print, Internet)
- 8. Is there any existing research that you know of regarding message design and delivery for kids with disabilities?
- 9. Based on your experience in working with kids with disabilities, whom do you suggest we talk with to test our messages? How do we get representation from kids with disabilities?
  - Are children with disabilities recruited by type of disability, degree of disability, etc.)?
- 10. What kids need special attention in YMC messaging (i.e., hearing impaired, mobility impaired, etc.)?

- 11. How could we include kids with disabilities into the YMC activities and events, while being sensitive to their needs, wants, and constraints?
- 12. How can we include parents/caregivers/families of disabled youth in our other messaging?
- 13. Can you direct us to individuals or groups of kids with disabilities who do prosocial and physical activities that we could highlight in our messaging and/or with whom we could test our messages?

### **APPENDIX B: Relevant Organizations for Individuals with Disabilities**

The following organizations promote physical activity to individuals with disabilities, offer programs for such individuals, and/or develop and disseminate messages for individuals with disabilities.

America's Athletes with Disabilities (AAD), http://www.americasathletes.org/

Center for Disability Policy and Research, Quality of Life Issues for Adolescents with Disabilities Group, University of Washington, http://depts.washington.edu/cdpr/

Family Voices, http://www.familyvoices.org/

The Frank Porter Child Development Institute of the North Carolina Office on Disability and Health, http://www.fpg.unc.edu/

International Wheelchair Basketball Association, http://www.iwbf.org/home.htm

**Nations Capital Handicapped Sports** 

**National Center on Physical Activity and Disability**, part of the Department of Disability and Human Development in the College of Applied Health Science at the University of Illinois at Chicago, <a href="https://www.ncpad.org">www.ncpad.org</a>

National Wheelchair Basketball Association, http://www.nwba.org/

**Technical Assistance Alliance for Parent Centers**, http://www.taalliance.org/index.htm

**U.S. Paralympics,** http://www.usparalympics.org/

### **USTA Wheelchair Tennis**,

http://www.usta.com/communitytennis/fullstory.sps?iNewsid=14207&itype=946&icategoryid=2 13

WE Media, http://www.wemedia.com/

World Team Sports, http://www.worldteamsports.org/

\*\*This list contains links to other Web sites outside of cdc.gov. The CDC is not responsible for the content or information collection practices of the Linked Sites, whether or not the CDC is affiliated with sponsors of the Web sites in any way.

### **APPENDIX C: Select List of Key Disability Print Media Outlets**

### **ABILITY**

Costa Mesa, California Telephone 949-854-8700 Fax 949-548-5966 www.abilitymagazine.com

### ACCENT ON LIVING

Bloomington, IL Telephone 309-378-2961 E-mail: acntlvng@aol.com

ARClight Magazine Congers, NY Telephone 845-267-2500 E-mail: www.rocklandacr.org

### **EXCEPTIONAL PARENT**

River Edge, N.J. Telephone 201-489-4111 Fax 201-489-0074 E-mail: www.eparent.com

NEW MOBILITY Santa Monica, California

Fax 503-253-1996

E-mail: www.newmobility.com

### PARAPLEGIA NEWS and SPORTS 'N SPOKES

Phoenix Arizona Telephone 602-224-0500 x11 Fax 602-224-0507 E-mail: cliff@pnnews.com or www.pn-maganize.com

### Appendix D: Useful Websites for Detailed Information Related to Disabilities

\*\*This list contains links to other Web sites outside of cdc.gov. The CDC is not responsible for the content or information collection practices of the Linked Sites, whether or not the CDC is affiliated with sponsors of the Web sites in any way.

1. <a href="www.ncpad.org">www.ncpad.org</a> (National Center on Physical Activity and Disability) (NCPAD) NCPAD is a part of the Department of Disability and Human Development in the College of Applied Health Sciences at the University of Illinois at Chicago.

This Web site includes:

A monograph by Tip Ray entitled "Principles for Adapting Activities in Recreation Programs and Settings," final reports of CDC-funded research on physical activity and disability; resource directories (searchable directories of organizations, programs, and facilities that provide opportunities for accessible physical activity, adaptive equipment vendors, conferences and meetings, references to journal articles, books, videos, and more); fact sheets on a variety of physical activities for people with disabilities; bibliographies (lists of selected topics concerning physical activity and disabilities; "In the news" media coverage about physical activity and disabilities; NCPAD monthly newsletter by E-mail; and an on-line media presentation entitled "Resources and examples of how to adapt exercise and physical activity equipment."

2. www.dusa.org (Disabled Sports USA)

This Web site includes:

A description of the organization; a list of contacts with Disabled Sports Organizations and Community-Based Organizations; membership; "Challenge" maganize; biographies of Athletes with Disabilities; partners and sponsors; legal information; chapter listings; links to other organizations; frequently asked questions; a schedule of upcoming events; spring summer, winter Sports programs; and Paralympic games results.

3. <u>www.americasathletes.org</u> (America's Athletes with Disabilities)

This Web site includes:

A newsletter (several issues of which are available for viewing through the webmaster); the organization's Disability Awareness Education Program; the organization's youth programs (a series of grants given every year to help children with disabilities uncover their athletic abilities; and a National Athletic Registry (created and maintained in conjunction with WE MEDIA).

### **APPENDIX D (Cont.)**

4. www.wemedia.com (WE MEDIA)

This Web site includes:

A section describing the organization, and such major recurring sections as (1) an editorial section including news and features, an interactive sub-section called The WE forum, and sports; (2) an information section including "accessible solutions" "politics and advocacy", resources and a "kids" section, and (3) a section on services-including careers, education, "house and home" and "money". An extensive directory contains much more.

5. <u>www.taalliance.org</u> (Technical Assistance Alliance for Parent Centers)

This Web site includes:

A description of the Alliance, which is federally funded under the Individuals With Disabilities Education Act (IDEA) and has Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs) in each state; detailed contact information; a section called "what's new", a calendar of events, a newsline; a section called "federal news"; a list of centers of expertise; a list of funding opportunities; weblinks and resources; data collections, evaluations, and surveys; and a resource database.

6. www.yqol.org (Center for Disability Policy and Research, University of Washington)

This Web site includes:

A home page that provides a description of the Center (the yquol in the website listing stands for "Youth Quality of Life", which pretty well describes the work of the Center); a section called "about us " which further describes the research emphasis of the Center, involving quality of life issues related to adolescents with disabilities; and a listing of current projects. The home page invites e-mails and other direct contact, and suggests that much more information is available on a customized basis upon request.

7. <u>www.usparalympics.org</u> (U.S. Paralympics, a Division of the U.S. Olympic Committee)

This Web site includes:

A description of the organization; a listing of the sports featured in its program; a list of the athletes on its 2002 team (which might provide examples of successful disabled athletes or additional spokespersons for media purposes); a calendar of events and locations for the current year; and an update section for recent relevant news.