



# Closing the Gap

A newsletter of the Office of Minority Health, U.S. Department of Health and Human Services

## Improving the Quality of Life for Minorities with Disabilities

By Michelle Meadows

Approximately 54 million Americans have some type of disability. Before the Americans with Disabilities Act (ADA) passed in 1990, people with disabilities struggled to gain equal access to education, employment, social services, and health care. But their fight continues. Today, there are 5.5 million people with disabilities who are uninsured. People with disabilities, especially those who are minorities, are more likely to be unemployed. And, there are many schools and public buildings around the nation that are still not ADA compliant.

In an effort to increase advocacy training and improve services for minorities with disabilities across the country, leaders of the National Urban League presented a proposal to Federal agencies at a meeting in Washington, DC, in October 1999.

The plan would call for Federal support to reach minorities with disabilities at all 115 affiliates of the League over the next six years. Founded in 1916, the National Urban League is a social service and civil rights organization with affiliates in 34 states and the District of Columbia. The League serves African Americans and other racial and ethnic minority groups.

Federal representatives at the National Urban League's recent meeting included the Social Security Administration, the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and agencies of the U.S. Department of Health and Human Services (HHS) including the Health Care Financing Administration, and the Administration for Children and Families (ACF).

### Formalizing the commitment

The National Urban League passed a resolution in 1998 that formalized the organization's commitment to programming for minorities with disabilities. The move included designating the National Urban League of Nebraska as the National Technical Assistance Center and Information Clearinghouse for Minorities with Disabilities for the League. The National Urban League also formed a collaboration with the National Family for the Advancement of Minorities with Disabilities, a 300-member grassroots organization in Atlanta.

"What we're seeing is the evolution of the premier civil rights organization in this country as it becomes an advocate for people with disabilities," according to John McClain, PhD, associate vice chancellor for academic affairs and chief student affairs officer at the University of Nebraska Medical Center. Dr. McClain is also the evaluator of a three-year League grant from ACF's Administration for Developmental Disabilities. "The National Urban League is leading a movement that focuses on energizing minorities with disabilities and their families," he said.

"A big part of what we do involves educating minorities with disabilities about what they're entitled to under the law because many just don't know," said Fred Wright, vice president of operations for the Urban League of Nebraska and principal investigator of the ACF grant. "This involves both training our staff and empowering the people we serve."

Now in the second year of the ACF grant, the National Urban League of Nebraska has led disability training, education, and advocacy in Milwaukee and Madison, Wisconsin; Binghamton and Rochester, New York; and Omaha, Nebraska. The ACF funding supports outreach to 10 League affiliates over three years. Other funding sources are NIDRR and the President's Committee on the Employment of Persons with Disabilities.

*...continued on page 2*

The Office of Minority Health Resource Center has moved to Rockville, MD. We can still be reached at PO Box 37337, Washington, DC 20013; or toll-free at 1-800-444-6472. Our new local numbers are: 301-230-7874; fax 301-230-7198; or TDD 301-230-7199.



OFFICE OF PUBLIC HEALTH AND SCIENCE  
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

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# Closing the Gap for the Nation's Most Vulnerable Population

Guest Editorial By Thomas W. Chapman, MPH, FACHE

Over the last few years, the health care system and the Federal government have increased attention to socio-cultural barriers to health care access and how they affect the lives of minority and low-income Americans. Now more than ever, the government and the health care industry are taking a hard look at ending the disparities in access, health status, and quality of care. However, as our awareness of these issues increases, so does the recognition of an emerging subgroup: the 12.6 million children under age 18—prevalently male, African American, from low-income and single parent households—who suffer from chronic physical, developmental, behavioral, or emotional conditions.

A 1998 study published in *Pediatrics* (vol. 102, no. 1) revealed that these children with special health care needs represent 18 percent of the nation's population, yet present its most needy and vulnerable citizens, with complex medical, social, and educational needs that are pressing and difficult to coordinate.

For low-income and minority families, navigating the rapidly evolving health care system has always been a challenge. When these families include children with special health care needs, the task is magnified. These families face substantial obstacles to health care access such as lack of transportation and language barriers. For children with special needs, this often translates into missed appointments, poor patient compliance, and reliance on episodic health care—often in emergency rooms.

These barriers impact other aspects of these children's lives, carrying over from the sickroom to the classroom. Children with special health care needs experienced three times as many sick days in bed and school absences annually as those without special needs. According to the 1994 National Health Survey on Disability, an estimated 11 percent of these children were uninsured, and 6 percent were without a usual source of health care. Eighteen percent reported being dissatisfied with one or more aspects of care received at their usual source of care, and 13 percent had one or more unmet health needs in the past year.

There are at least 930,000 children receiving Supplemental Security Income (SSI), according to the Social Security Administration. There may be many more children who qualify for these benefits but for a number of reasons, do not receive them. In addition, new eligibility rules for SSI required by welfare reform legislation resulted in about 143,000 children losing their SSI eligibility by the end of 1997. Due to gaps in transitioning to the new system, many of these children may have lost their Medicaid benefits as well. According to Family Voices, a national advocacy

group for parents of children with special needs, although the Social Security Administration invited families to appeal, many were discouraged and confused by a review process that is complicated, lengthy, and requires expert legal assistance.

The Federal government is also encouraging states to enroll children with special needs who are SSI/Medicaid beneficiaries into managed care programs. But this policy comes with limited guidance and liberal guidelines on how best to serve this population in a competitive model. There does not appear to be a well-defined strategy focused on addressing the issues of transitioning families with special needs into the managed care system, nor a strategy focused on addressing the social needs which often undermine access to care.

## What can be done?

- The Federal government and states should support programs that involve children with special needs and their families in the planning and design of health care and outreach programs, particularly under the Title V Maternal and Child Health block grant and CHIP block grant programs.
- Managed care organizations and Medicaid agencies should be required to focus on well-organized coordination systems, customized provider networks with a focused number of experienced and capable organizations, and the development of primary care management programs, versus capitated arrangements.
- Regulation and implementation of the SSI program should be improved through development of enhanced outreach and education activities to insure that all children who need benefits will receive them, and that children who have been denied SSI will be tracked, and their situations resolved.
- We should fund and support efforts to develop comprehensive programs and wrap-around services that enable families of children with special needs to maximize access and efficiently utilize their time in managing their family's health needs.

*Mr. Chapman is director of the "Opening Doors: Reducing Sociocultural Barriers to Health Care" program, sponsored by the Robert Wood Johnson Foundation and the Henry J. Kaiser Family Foundation. Opening Doors funds and supports service and research projects to identify and break down non-financial, culturally-based barriers to health care. For more information, call (202) 974-4690.*

















## AIDS Hotline Signs on Deaf Consumers

By Jennifer Brooks

**D**eafness/hard of hearing is the second most common chronic health condition in the United States. More than 28 million Americans have some form of hearing loss, and 80 percent of those have irreversible and permanent hearing damage, according to the National Association of the Deaf. Yet the deaf community is an underserved “subculture” that often relies on other deaf people for health information.

The Centers for Disease Control and Prevention (CDC) established a National AIDS Hotline TTY Service to provide confidential and reliable information on HIV/AIDS and other STDs to the deaf community. This service is the only one of its kind in the country.

The following is an interview with Chad Ludwig, BSW, senior supervisor of the TTY Service.

**Q: Does the deaf community have special needs when it comes to obtaining health information?**

**Chad:** The deaf community is broken into sub-groups that have a variety of special needs when it comes to obtaining health information. It could be through written communication, TeleTYpe (TTY) communication, community’s grapevine, using interpreters, speech reading, verbal communication, and signed communication. But not every member within the deaf community is fluent in each of the modes of communication as mentioned.

It is the responsibility of each party to ensure that the health information is accessible. Normally, members within the deaf community are aware and familiar with the best methods of gaining health information. Health care providers should be attentive to their patients and make an attempt to fulfill their needs in obtaining health information.

**Q: What barriers to prevention and treatment information do deaf people face?**

**Chad:** The health care community either isn’t willing, doesn’t have the option, or lacks the resources or information to have the ability to fulfill the service needs of members within the deaf community by providing the health information. One report states that the average reading level among members of the deaf community is between the 4th and 5th grade levels. Many magazines, newspapers, captions on TV, brochures, and other information sources are written in English well above this reading level. This is another barrier to health information across the deaf community.

It is important to note that more than half of the United States has recognized American Sign Language (ASL) as a foreign language.

The ASL is commonly used by deaf people as their first language. The ASL is a visual language, and the way to express the information is a lot different than spoken English. To attempt to mix the spoken English language and ASL creates yet another barrier.

For example, a doctor had an interpreter present with a deaf patient who is living with HIV. The patient questions if he needs to finish his bottle of medicine. The doctor explained that he must finish it. The patient came back to the doctor for his quarterly visit and the doctor asked how he doing with the medicine. He said that he had finished it a while ago. The doctor questions why he didn’t have it refilled. He explained that he thought he only had to finish one bottle of pills and not the refills. This type of misunderstanding that had occurred between the patient and doctor—an information communication barrier—raises concern about the patient’s health.

**Q: What is the deaf community’s most common vehicle for obtaining information?**

**Chad:** A common vehicle for getting information to the deaf community is through the community grapevine. The grapevine may be viewed negatively, although it is very useful for many members within the deaf community. There are some members that don’t have access to written information. There are some members who are educated in certain specialties. There are some members who are actively involved in other areas. These members attend social gatherings, club meetings, and main events and would exchange information among the members so that the information could be constantly updated among themselves.

There are also many electronic bulletin boards, newspapers, magazines, and videotapes that are used to disseminate the information among deaf community members.

**Q: Are deaf people more or less at risk for HIV/STDs than other populations?**

**Chad:** Some research has shown that “high rates of substance abuse exists among the deaf community, one in seven (1 in 7) deaf persons has a history of substance abuse, compared to one in ten (1 in 10) in the hearing population.” Substance abuse can be a risk factor for HIV by lowering inhibitions and impairing judgement, which can lead to unsafe sexual behaviors. Sharing injection equipment is also a risk for HIV transmission. (See “What are risk factors for HIV?” in the University of California, San Francisco Center for AIDS Prevention Studies fact sheet, *What are deaf persons’ HIV prevention needs?*)

Did you know the OMH Resource Center has a TTD line? Call (301) 230-7199

Given that information, auditory and communication barriers could create risks for members of the deaf community to become infected with HIV/AIDS and sexually transmitted diseases (STDs). If a member cannot access spoken English and/or comprehend the English language, this could increase the risk of becoming infected with HIV/AIDS and STDs.

**Q: Are deaf people discriminated against in health care? As with many minority groups, is cultural competency an issue among deaf people trying to obtain health services?**

**Chad:** Discrimination occurs when a health care professional refuses to fulfill a deaf person's communication needs such as providing an interpreting service. Some deaf people attempt to obtain the health service and are refused just because they don't know the resource, information, or who to contact.

Some deaf people attempt to contact the health service by using the relay service, but are hung up on just because the health care facility was not able to handle the relay call or felt that it would take too much of their valuable time. And, a cultural issue may arise when language and/or communication becomes a barrier between a deaf person and a health care provider—this would make a deaf person feel that the service is not adequately fulfilling his or her needs.

**Q: How does the CDC National AIDS Hotline TTY Service address those issues and meet the health information needs of the deaf community?**

**Chad:** The CDC NAH is available as an information, resource, referral, and technical assistance service. It contributes to health care by providing a better service to the members within the deaf community.

**Q: Do you do any outreach to deaf minorities?**

**Chad:** Yes, the CDC NAH does outreach to the deaf minority community by promoting materials via the electronic mail,

Internet, newspapers, magazines, newsletters, mass mailings, mass e-mails, video conferences, group calls, classroom calls, and by participating in the deaf-related events such as conferences and community gatherings. By doing so, we increase the visibility that allows the deaf community to use the CDC NAH as an information, resource, referral, and technical assistant.

**Q: How does someone access the Hotline?**

**Chad:** Callers can access our service by using TeleTYpe (TTY) equipment. TTY is equipment that allows the individual to place a call to another party who has TTY equipment and/or using the Relay Service to get connected to another individual who doesn't have TTY. The TTY is a machine that allows an individual to effectively communicate the information to a person on another end. To access the CDC NAH's TTY Service, one needs to use either TTY or relay service to get through to the TTY operator.

**More information:** The CDC NAH is operated under contract by the American Social Health Association (ASHA). For further information write to P.O. Box 13827, Research Triangle Park, NC 27709, or browse the Web site: <http://www.ashastd.org>; or the teen Web site: <http://www.iwannaknow.org>. Access the hotline at 1-800-AIDS-TTY; 919-361-8454 TTY; 919-361-8484 TTY2; 919-361-4855 FAX

Note: between December 15th and the end of this year, the ASHA will be launching a new, video-enhanced Web site which allows ASL users to click on the Internet and be able to view signed information and prevention messages on HIV/AIDS.

*In addition to his role at the CDC National AIDS Hotline, Chad Ludwig is chair of the National Coalition on Deaf Community and HIV/AIDS (NCDH). He can be contacted by e-mail at: [chadludwig@earthlink.net](mailto:chadludwig@earthlink.net). The NCDH's address is - Dann Trainer, IV; NCDH Secretary; PO Box 8401; Minneapolis, MN 55408.*

## CDC National AIDS Hotline TTY Service

Many people have questions about HIV/AIDS and don't know where to get answers. The CDC National AIDS Hotline TTY Service can help.

- Trained staff are available to answer questions and talk about HIV and AIDS and other sexually transmitted diseases.
- They can mail informational brochures that explain details about HIV and AIDS testing, prevention, and more.
- They can put people in touch with many different services all over the country.

**1-800-243-7889**

**All calls are free and private.**



### Camden City Hispanic Women's Resource Center

Hispanic Health and Mental Health Assoc.  
Of Southern New Jersey  
2700 Westfield Avenue  
Camden, NJ 08105  
609-365-7393

### Chicano Awareness Center

4821 South 24th Street  
Omaha Nebraska 68107  
402-733-2720

### AboutFace U.S.A.

1407 and 1/2 North Wells Street  
Chicago, IL 60610  
312-337-0742  
(Facial disfigurement issues and advocacy)

### Acoustic Neuroma Association

P.O. Box 12404  
Atlanta, Ga. 30355  
(404) 237-8023  
(Neurological disorders, audiology)  
<http://ANAUUSA.org>

## Web Sites

### National Institute on Disability and Rehabilitation Research (NIDRR)

<http://www.healthfinder.gov>

### American Indian Rehabilitation Research and Training Center (AIRRTC)

<http://www.nau.edu/ihd/airrtc>

### Disability Statistics Rehabilitation Research Training Center

<http://dsc.ucsf.edu>

### Family Village Project

<http://www.familyvillage.wisc.edu>  
(Advocacy & Public Information for children with special health care needs)

### Disability Information & Resource Centre

<http://www.dircsa.org>

### Mental Health Net

<http://www.cmhc.com>

## Publications

### *Job Hunting Tips for the So-Called Handicapped*

By Richard Nelson Bolles  
Ten Speed Press, 1991  
800-841-2665

### *Job Strategies for People with Disabilities*

By Melanie Astaire Witt  
Peterson's Guides, 1992  
800-338-3282

### From the National Organization on Disability

910 Sixteenth Street, NW Suite 600  
Washington, D.C. 20006  
(202) 293-5960; (202) 293-5968 (TDD)  
<http://www.nod.org>

- *Guide to Organizing a Community Partnership Program* - Describes the role of a Community Partner and provides easy to follow tips and checklists. 24 pages. 1997.
- *Community Partnership Program Fact Sheet* - Facts and general information on the Community Partnership Program. 2 pages. Updated yearly.
- *Start on Success Program Brochure* - Facts and general information on internships for students with disabilities. 2 pages.

### National Association of Social Workers

202-408-8600  
202-408-8396 (TTD)  
<http://www.naswdc.org>

- *Information packet for social workers on the Individuals with Disabilities Education Act*. Provides an analysis of the 1997 amendments and implications for Social Workers. To obtain, send a self-addressed, standard #10 envelope with \$.78 postage to NASW, Information Center, requesting "ADA Information Packet."

## Parent Training and Information Centers

These centers are part of the Parent Advocacy Coalition for Educational Rights (PACER).

### Northeast Regional Center

Parent Information Center  
(603) 224-7005 voice

### Midwest Regional Center

(740) 382-5452 voice  
(740) 383-6421 fax

### South Regional Center

Partners Resource Network, Inc.  
(409) 898-4684 voice

### West Regional Center

Matrix Parent Network and Resource Center  
(415) 884-3535

Source: Alliance Coordinating Office, PACER Center

## OMH-RC Expands HIV/AIDS Information Services

With funding from a partnership between the U.S. Department of Health and Human Services and the Congressional Black Caucus, the Office of Minority Health Resource Center (OMH-RC) is expanding its services related to HIV/AIDS. The expansion includes the recent addition of staff who specialize in HIV/AIDS information dissemination and outreach. OMH-RC will develop new HIV/AIDS publications, including a quarterly newsletter on HIV/AIDS that will be released in February 2000.

If you aren't already on our mailing list, call 1-800-444-6472 to join. You can also request free publications and database searches on HIV/AIDS and other minority health topics. In addition, OMH-RC invites health professionals who specialize in HIV/AIDS to call and request an application for the Resource Persons Network—a group of experts who volunteer technical assistance on minority health issues.

We've moved! OMH-RC has new local phone numbers: (301) 230-7874; or fax (301) 230-7198; TDD (301) 230-7199.

**DEPARTMENT OF HEALTH & HUMAN SERVICES**

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# *Closing the Gap*

## Conferences: Year 2000

**Jan 24-28:** Partnerships for Health in the New Millennium: Launching Healthy People 2010. For information, visit conference Web site: <http://www.health.gov/partnerships>.

**March 5-8:** 13th Annual Conference, *System of Care for Children's Mental Health*. Sponsored by the Research and Training Center for Children's Mental Health. Clearwater Beach, FL. Contact: 813-974-4661.

**March 6-7:** 16th Annual Pacific Rim Conference on Disabilities, *PAC RIM 2000 Creating Futures*. Presented by The Center on Disability Studies, Hawaii University Affiliated Program. Hilton Hawaiian Village Hotel, in Honolulu. Contact: 808-956-2673 or 956-5715.

**March 23-25:** Conference, *Stepping Forward: Creative Approaches in Prevention, Treatment, and Recovery for Deaf People*. Minneapolis, MN. Contact: MCDPDHII, 2450 Riverside Ave, Minneapolis, MN 55454.

**April 3-4:** *6th Annual Statewide Assistive Technology Exposition and Conference*. Sponsored by the Missouri Assistive Technology Project. Held in Columbia, MO. Contact: 816-373-5193 (V); 373-9315 (TTY); [matpmo@qni.com](mailto:matpmo@qni.com).

**May 3 - 4, 2000:** *Touch the Future 2000 Expo: Unity Through Diversity*. Macon Centreplex, Macon, GA. Contact: Tools for Life, 404-657-3082.

**May 4 - 7, 2000:** *International Parent to Parent Conference 2000*, brings parents and professionals together from around the world together to share and learn how best to support families and develop best practices for people with disabilities. Hilton Casino and Resort, Reno, NV. Contact: 702-784-4921, ext. 2352; [cdinnell@scs.unr.edu](mailto:cdinnell@scs.unr.edu).

**July 17 - 21, 2000:** *ICCHP 2000 International Conference on Computers Helping People with Special Needs*. Conference topics include communication, medicine, environment, and rehabilitation technology. Universitat Karlsruhe, Germany. Contact: Irene Sudra, Austrian Computer Society, 43-1512-02-35-12 [irene.sudra@ocg.at](mailto:irene.sudra@ocg.at).

The editors of *Closing the Gap* welcome your story ideas.

If you have a community program, special event, news or resource item you would like featured, please fax or e-mail Houkje Ross at 301-495-2919; [houkjer@omhrc.gov](mailto:houkjer@omhrc.gov).