



Improved Care for Neglected Population Must Be “Rule Rather Than Exception”

Rebecca Voelker

AS THE DIRECTOR OF A PROGRAM aimed at training health care professionals to treat children with developmental disabilities, Kathleen Braden, MD, is all too familiar with physicians' deficits in caring for these special patient populations. As one example, she recalls a young woman in the emergency department with status epilepticus. Despite her unremitting seizure, the woman was triaged to the side for a long time. Her family became very upset, and tried to alert emergency personnel to the fact that she needed immediate medication to prevent severe brain damage.

Because the woman had mental retardation, the features of her seizure were seen as “just the way she always is,” says Braden. “If someone who was not mentally retarded had come in with a seizure that was out of control and said, ‘Stop it now!’ it would have been seen as an emergency. This woman was triaged to the side because of her mental retardation.”

Throughout the United States, thousands of other adults and children with mental retardation and other developmental disabilities face tremendous obstacles in gaining access to appropriate, quality health care. The barriers are many, and they are complex. Inadequate physician training is partly the cause; threadbare reimbursement rates through Medicaid exacerbate the problem. The time limits of managed care make matters worse. Obtaining informed consent from those with mental retardation is difficult at best, so they have not been enrolled in clinical trials that might show if standard treat-

ments affect them any differently than the general public.

“There is no standard of care, so how do we know what the best practices are?” asks Braden, director of a Leadership Education in Neurodevelopmental and Related Disorders (LEND) training program that is affiliated with the University of Massachusetts Medical School, Worcester.

“ALWAYS NEGLECTED”

Poor health care for people with mental retardation has been the rule rather than the exception. “These patients have always been neglected by the medical profession,” says Robert Cooke, MD, former chief of pediatrics at Johns Hopkins Hospital and a senior medical adviser to Special Olympics Inc. Prior to the 1960s and 1970s, when institutional living was the norm, medical staff in the institutions tended to the mentally retarded and developmentally disabled. Granted, the care wasn't always of the highest quality. Some institutions were accused of using their clients inappropriately in medical experiments. Even so, says Cooke, “The care of the more severely disabled was more adequate than what's happening now. They were able to provide day-to-day supervision.”

In today's postmainstreaming era, the trend in living arrangements is toward small residential settings such as group homes or foster care. Data from the State of the States Project, which is affiliated with the University of Colorado's Coleman Institute for Cognitive Disabilities, show the trend.

From 1996 to 2000, the number of people living in these residential settings increased by 11%, to 433 799. But

the numbers living in public and private institutions with 16 or more individuals decreased by 15%. In 1996, 51% of those using residential services were in settings for six or fewer people. In 2000, that figure rose to 61%, representing 263 359 individuals.

It's unlikely that small residential settings have onsite medical personnel, and trained health care professionals may not be within easy reach. “It's not uncommon in rural settings to climb into a van with the people you live with and drive 100 or 200 miles to go to the dentist,” says Charlie Lakin, PhD, director of the Research and Training Center on Community Living at the University of Minnesota.

As this demographic shift took place over the last 30 or more years, the US health care system didn't take notice. Physicians are unprepared because medical schools generally don't teach students how to care for people with mental retardation. The curriculum, says Lakin, “already is jam-packed and growing on a daily basis.”

Deborah Danoff, MD, associate vice president of the medical education division at the American Association of Medical Colleges, says medical schools have improved course content in communication skills, especially with patients whose health literacy is limited. The more sophisticated skills needed to treat patients with mental retardation may be better addressed during residency, she notes. “The learning that begins in medical school doesn't end on graduation day,” she adds.

Says Lakin, “It's not that medical schools have consciously rejected this, they just haven't consciously considered it.” And because of the lack of for-



Robert Eddy



Betsy Hannah, LPN, and Louis DiNicola, MD, with two of their patients at Gifford Medical Center. (Reproduced with permission from *Exceptional Parent Magazine*)

mal training, many physicians aren't at ease with patients with mental retardation. "Physicians are uncomfortable, and they don't encourage [people with mental retardation] to become part of their practice," says David Coulter, MD, attending neurologist at Children's Hospital in Boston. Physicians aren't the only ones who are uncomfortable. "Other patients say, 'I don't want to be in the waiting room with them; I don't want my kids exposed to them.' There is fear, they don't understand the rocking and the noises," says Sheryl White-Scott, MD, director of the St Charles Developmental Disabilities Program at St Vincent's Catholic Medical Centers of New York.

Discomfort and lack of training are compounded by low reimbursements from Medicaid, which covers a large portion of the population with mental retardation. An office visit with a patient with mental retardation takes at least twice as long as with a patient from the general population, says White-Scott, adding that while a primary care doctor can see 20 patients in 3 hours in the general population, she, even with her extensive experience, would book only 10 patients with mental retardation in the same time period.

LEND SUPPORT FOR CHILDREN

Since the late 1960s, the federally funded LEND program has served as a clinical training forum in the care of children with developmental disabilities. Thirty-six LEND programs are affiliated with tertiary care hospitals in 29 states. The programs, says Braden, "create cadres of trained people who understand the is-

suess these children and families face in finding services to address special medical problems, coordinate care, and advocate for families."

Program leaders would like to have one program in every state, but with just \$17 million in total funding, the coffers are too small. The nonprofit Association of University Centers on Disabilities supports a network of university centers that sponsor programs directed toward the mentally retarded and developmentally disabled. In addition to the LEND programs, they include the University Centers for Excellence in Developmental Disabilities Education, Research and Service, which work to further community inclusion, and the Developmental Disability Research Centers, which focus on biomedical and behavioral research.

In some areas, pediatrics specialists have adopted the "medical home" concept supported by the American Academy of Pediatrics and the federal Maternal and Child Health Bureau to provide special attention for developmentally disabled children. Among them are pediatrician Louis DiNicola, MD, and care coordinator Betsy Hannah, LPN, at Gifford Medical Center in Randolph, Vt.

DiNicola and Hannah work to combine health care and an array of other services under one roof. Their problem-solving powers range from offering a balloon to an anxious child to helping parents arrange for speech therapy. "I treat the children with respect, not like they're second class citizens," says DiNicola. Parent Kim Daniels agrees. Three of her children have been DiNicola's patients.

"Lou educated me," she says. "He said, 'You'll know what's best for your child.'"

However, with LEND programs aimed at training in pediatric care, little is available in training to care specifically for adults with mental retardation. "The training of [physicians] to take care of adults with mental retardation is almost zero," says Cooke.

In a 2001 report, *Promoting Health for Persons with Mental Retardation: A Critical Journey Barely Begun*, Special Olympics Inc addressed the issue of health disparities among people with mental retardation. (The report may be obtained by sending an e-mail request to mwagner@specialolympics.org or writing to Mark Wagner, MD, Special Olympics, Inc, 1325 G St, NW, Suite 500, Washington, DC 20005.) Data from the Special Olympics Healthy Athletes screening program has shown that participants in Special Olympic events have had inadequate vision assessments, and they have a high prevalence of oral pain—20% in one group of 2200 athletes screened. In another group of 529 athletes, 26% failed their hearing tests. In the general population, the expected failure rate would be under 5%.

Special Olympics commissioned researchers at Yale University to compile a literature review of health status in people with mental retardation. With perhaps the exception of obesity, which is higher in people with mental retardation, and leukemia, which affects more children with Down syndrome than in the general population, people with mental retardation don't appear to be disproportionately affected by most major illnesses, such as cardiovascular disease and cancer. Persons with certain syndromes of cognitive impairment are more vulnerable to such health problems as impacted bowels, infected teeth, and others listed in the sidebar (p 301).

What's disproportionate is the care delivery system. "The more damaging effects on this population are from managed care and the [lack of] coordination of care among providers," says Bonnie Kerker, PhD, an author of the review and a senior research associate at Casey Family Services in Shelton, Conn.



SURGEON GENERAL TAKES NOTICE

Data from the Special Olympics and Yale reports provided a crucial understanding of the issues when former Surgeon General David Satcher, MD, PhD, convened the Surgeon General's Conference on Health Disparities and Mental Retardation on December 5-6, 2001, in Washington, DC.

"The Special Olympics invited me to Alaska for the [games] more than a year ago. Senator Ted Stevens (R, Alaska) had a hearing there on the health needs of the mentally retarded so I was forced, if you will, to at least look at this issue," Satcher recalls. "When I met with parents in Alaska and heard from them their struggles in trying to get health care for their children, or for adults with mental retardation, I came away from there knowing I had to do something."

The National Institute of Child Health and Human Development was a lead organizer of the conference. Its director, Duane Alexander, MD, recognizes the challenges that lie ahead in changing reimbursement schedules and training physicians. The Surgeon General's conference, he says, was an opportunity to showcase a few programs that have made inroads in providing quality care. "We have to make this the rule rather than the exception," he says.

A report from the Surgeon General's conference, *Closing the Gap: A Na-*

Under-Recognized Health Problems in People With Mental Retardation

To help ensure adequate medical care, the Shriver Center for Developmental Disabilities at the University of Massachusetts Medical School has prepared the following list of conditions that often go undetected in people with mental retardation.

- **Gastrointestinal problems:** Dysphagia, esophagitis, constipation, bowel impaction.
- **Sensory impairments:** Visual and auditory.
- **Chronic/recurrent infections:** Most commonly sinusitis and otitis media.
- **Oral disease:** Infected teeth, periodontal disease. Referred pain may affect behavior or function.
- **Respiratory tract diseases:** Chronic obstructive pulmonary diseases.
- **Musculoskeletal conditions:** Degenerative joint disease, osteoporosis. Long-term polypharmacy may contribute to these conditions.
- **Neurological conditions:** Compressive neuropathies from contractures or use of walkers. Seizure disorders.

Approximately 30% of adults with mental retardation and developmental disabilities have syndromes and unique health problems that require additional screening. They include:

- **Down syndrome:** Attention should be directed toward hearing problems (which occur in up to 50% of such individuals), ocular problems (up to 50%), hypothyroidism (15%), seizure disorders (5%-10%), atlantoaxial instability (10%), and premature senescence (increased rate).
- **Cerebral palsy:** Strength and range of movement should be monitored regularly. Particular attention should be paid to areas of swallowing and bowel function in people who are not independently mobile.

Source: Shriver Center for Developmental Disabilities, University of Massachusetts Medical School. Distributed by the Massachusetts Department of Mental Retardation.

tional Blueprint to Improve the Health of Persons with Mental Retardation, is available at <http://nichd.nih.gov/publications/> or by calling (800) 370-2943.

Coming next week: Perhaps the greatest challenge to those caring for

patients with mental retardation is effectively diagnosing and treating those who also have mental illness. Experts discuss the problems clinicians face and new research that may yield treatment advances. □

Can Massive Prevention Efforts Avert 29 Million New Cases of HIV by 2010?

Joan Stephenson, PhD

WHEN PUBLIC HEALTH EXPERTS attempt to forecast what the state of the global HIV/AIDS pandemic will be at the end of the decade, they see two alternate futures—with 29 million lives hanging in the balance. In one scenario, the world continues to deploy prevention measures in a relatively piecemeal fashion, reaching only one in five people who are at risk of infection. In the other

scenario, the global community engages in a massive scaling up of prevention activities, an effort that proponents say could reduce cumulative new infections by more than 60% by 2010.

Both scripts are based on projections by an international group of researchers, published in the July 6, 2002, issue of *The Lancet*. The script with the more favorable outcome is one proposed by a new report, *Global Mobilization for HIV Prevention: A Blueprint for Action*, by the Global HIV Prevention

Working Group. The group, convened by the Bill and Melinda Gates Foundation and the Henry J. Kaiser Family Foundation, comprises experts in public health, biomedical, behavioral, and social research, representatives of United Nations agencies, and advocacy groups for people living with HIV/AIDS. The report was made public immediately before the XIV International AIDS Conference in Barcelona.

"We really do know what works for prevention—there's overwhelming



evidence of what's successful," said Helene Gayle, MD, MPH, of the Gates Foundation in an interview. "What we haven't done is apply what we know."

CAN PREVENTION EFFORTS BEAT HIV?

What seems clear is that without an HIV vaccine in hand and in the absence of a major scaling up of prevention programs, the HIV/AIDS pandemic will continue to devastate sub-Saharan Africa and expand swiftly in places such as Russia, China, and India. According to projections by the authors of *The Lancet* article, 45 million people will become newly infected with the virus between 2002 and 2010 if the pandemic continues on its current course.

However, the researchers also predict that this catastrophic expansion of the pandemic could be reduced by 64%—29 million fewer infections by the end of the decade—if the level of activity involving a comprehensive package of existing HIV prevention strategies as well as care and support programs is vigorously increased by 2005.

"We're years from having a vaccine, we don't have a microbicide, and there are other tools we need to continue to develop," said Gayle. "But in the meantime, there's a lot that we can do that can make a difference today to prevent those 29 million new infections."

Some countries and individual programs have done a good job of proving that prevention works. For example, after Thailand launched a national prevention program that included a "100% condom use" approach to targeting brothels, broad-based efforts to raise public awareness of HIV prevention, and human rights protections for people infected with the virus, the number of new infections fell by 80% by the end of the 1990s from levels reported before Thailand's national prevention program was mobilized. In Uganda, where prevention efforts were spearheaded by President Yoweri Museveni and featured visible participation by nongovernmental organizations and people living with HIV/AIDS, the country carried out a comprehensive prevention program involving extensive public aware-

ness efforts and condom use promotion, as well as free access to voluntary counseling and testing. The result: between the start of the 1990s and the end of the decade, HIV prevalence decreased by nearly two thirds in urban pregnant women, and national HIV prevalence was slashed nearly in half.

A BLUEPRINT FOR PREVENTION

The Global HIV Prevention Working Group's report outlines a range of HIV prevention interventions to reduce the spread of the virus through the various routes of transmission: sexual contact, exposure to infected blood products, exposure through injection drug use, and mother-to-child transmission.

Some of the strategies mentioned include: programs to encourage safer sexual behaviors (such as delaying sexual activity or reducing the number of partners); promoting condom use; preventing and treating sexually transmitted diseases; making voluntary counseling and testing available; implementing policies to safeguard blood supplies; treating injection drug users; establishing syringe and needle programs; and offering drug treatment to prevent infected mothers from transmitting HIV to their infants.

It's not clear how feasible some of the interventions would be in various settings and among different populations across the globe. For example, much depends on factors that are beyond the control of even the most ardent prevention-oriented local, national, and international health agencies and nongovernmental organizations, such as a lack of strong national leadership endorsing HIV/AIDS prevention efforts or the presence of civil wars or other conflicts in areas that desperately need help. But proponents say that prevention campaigns are more likely to be successful if they attack the problem from many different angles.

"We need a combination approach, and an integrated approach," explained Gayle. Just as highly active antiretroviral treatment regimens use a combination of drugs that attack HIV at different phases of its life cycle, pre-

vention programs must integrate a range of interventions proven to make a difference.

The report also presents a series of recommendations for scaling up global HIV prevention efforts. One crucial element, as successes in Thailand, Uganda, and elsewhere have demonstrated, is vocal political leadership. Other key factors include substantially increasing and sustaining funding for prevention measures; training local personnel and providing the necessary technology to build up local capacity to carry out prevention programs; helping developing countries to carry out effective HIV/AIDS surveillance and to tailor prevention strategies accordingly; expanding access to key prevention tools such as condoms and HIV test kits; tackling social factors such as stigma, poverty, and women's status; and increasing funding and other incentives to accelerate research on new technologies (such as vaccines or microbicides) for preventing HIV infection.

The report will be widely distributed to countries and nongovernmental organizations in both developed and developing countries, and posted on the Gates and Kaiser foundations' Web sites (<http://www.gatesfoundation.org/> and <http://www.kff.org/>).

Experts have estimated that full implementation of a comprehensive global HIV prevention program would cost about \$4.8 billion annually (*Science*. 2001;292:2434-2436). But delay in scaling up efforts to this level would be costly in human terms. According to projections by the authors of the *Lancet* article, a 3-year delay—that is, full implementation by 2008 rather than 2005—would reduce the total number of new infections averted by 50%.

"If we do what we know works, and are able to get the resources and the political commitment and the human capital together to scale it up, then we could have [16 million new infections] by 2010 rather than 45 million," said Gayle. But if the world community fails to take such action, "we ought to be ashamed of ourselves," she said. □



WHO Declares the Individual's Right to Be Safe

Mike Mitka

MONTREAL—Is “safety” a human right?

Attendees at the World Health Organization (WHO) Conference on Injury Prevention and Control think so. This spring, they approved the *Montreal Declaration: People's Right to Safety*.

The 11-article document, which could be adopted by the United Nations, states: “Safety is a fundamental right. It is essential for the attainment of health, peace, justice, and well being.”

Worldwide, nearly 6 million people die annually from unintentional injuries, making trauma the second leading cause of death after cardiovascular diseases. Road injuries, suicide, homicide, war, drowning, fire, and intoxication are the most frequent causes of injury death. And while many would say such deaths are often accidental, others disagree, arguing that someone or something created the environment that made the injury possible.

Many in the health care community believe most injuries can be avoided. This opinion led the *British Medical Journal* to ban inappropriate use of the word “accident,” with the journal's editors arguing that most injuries are preventable (*BMJ*. 2001; 322:1320-1321). The *Journal of the American Medical Association* and the specialty *Archive* journals of the AMA pioneered in avoiding use of the word (Young R. In: *American Medical Association Manual of Style*. 9th ed. Baltimore, Md: Williams & Wilkins; 1998:243-270). In this evolving atmosphere, proponents of the *Montreal Declaration* said their document can help persuade governments and corporations that they have a duty to protect citizens and consumers, and if they do not do so, they will be held accountable.

“I believe that this *Declaration* is a platform from which many advocates for the prevention and control of inju-

ries, including health professionals as well as human rights activists, can approach their governments to seek and obtain recognition and support in dealing with the issue of injury in their respective countries,” said Diego E. Zavala Zegarra, PhD, of Puerto Rico, a representative of Amnesty International USA.

The *Declaration* defines safety as “a state in which hazards and conditions leading to physical, psychological, or material harm are controlled in order to preserve the health and well-being of individuals and the community.” It says also: “Safety is the result of a complex process where humans interact with their environment, including the physical, social, cultural, technological, political, economic, and organizational environments.”

A POLITICAL ISSUE, TOO

When debating the *Declaration* in Montreal, attendees took part in a sometimes passionate discussion about what the document should stand for. On one side were those who wanted a statement centered on safety as it concerns individuals in matters such as improving automobiles, playground equipment, and home design (the absence of safeguards in such things leading to conditions that meet the usual definition of “unintentional injury”).

On the other side were people advocating a document that put on alert governments that allow terror campaigns against their citizens and multinational corporations that create substandard manufacturing facilities in Third World countries (conditions that were described as “intentional injury”).

Compromise was required for the *Declaration* to gain acceptance in the international community. Conference participants agreed that it would be difficult for a health care advocate to take a document highly critical of terror regimes back to a country ruled by a despot.

“The *Declaration* is an enabling document to take forward any way you want,” Dinesh Mohan, PhD, of India, chair of the *Declaration* committee, told attendees. “There must be consensus, and it may not be against any government.”

Leif Svanström, MD, PhD, of the Karolinska Institute in Sweden and a member of the WHO Collaborating Centre on Community Safety Promotion, said “Let's stick to safety,” since many international declarations already argue for the protection of people in troubled areas. Svanström noted that the *Montreal Declaration* references many of these other documents, including the *Universal Declaration of Human Rights*, the *International Covenant on Civil and Political Rights*, and the *United National Declaration on the Protection of Women and Children in Emergency and Armed Conflict*.

Still, Zegarra argued that the *Montreal Declaration* should also be a tool used for larger issues.

“This *Declaration* is not binding on governments or corporations,” Zegarra said. “However, the usefulness of this *Declaration* is the fact that it comes from health [professionals] and other related professionals who are working on injury prevention and control around the world. Thus it would be difficult for government or corporate officials to dismiss this *Declaration* without provoking a response from concerned organizations and individuals.”

DECLARING A RIGHT

The *Montreal Declaration* asserts right-to-safety principles and lays out various factions' responsibilities to ensure compliance.

“The introduction, expansion or continuation of unsafe or hazardous activities or structures into an environment should be based upon the informed consent, given without fear or undue influence of any kind, of the community likely to be affected by such action,” the document states. “People have the right to participate, individually and collectively, in the planning,



design, implementation and evaluation of all activities that may affect their safety and well being.”

If people are injured, they should be compensated by the responsible parties, the *Declaration* maintains. “Adequate mechanisms shall be established to provide relief and compensation to all persons injured or otherwise detrimentally affected by an unsafe or hazardous activity. The mechanisms so established shall provide for the right to fair and adequate monetary compensation.”

Mohan said the philosophy behind issuing the *Declaration* is to counter the fact that people are losing control over

their personal safety as society modernizes.

“In modern ways of living, individuals do not have many choices about when and where they should travel, the design of where they live and work, and for getting informed information about the hazards of products they use,” Mohan said. “Therefore, individuals have a right to demand that their lives be made much safer when they use public spaces and products sold to them.”

GOVERNMENT AS GUARANTOR

And, he said, safety rights should come from governments.

State responsibilities include implementing laws and rules protecting people’s right to safety against any violation by agencies, including corporate bodies.

“This document is a strong statement for health and human rights advocates to lobby their home governments to obtain and secure government’s support for injury prevention and control initiatives,” Zegarra said. “Oppressive regimes, guerrilla and paramilitary forces, would be faced with an international *Declaration* that hopefully will gain strength as it is promoted through the United Nations.” □

MISCELLANEA MEDICA

- **Raymond M. Dunn**, MD, has been appointed chief of the Division of Plastic Surgery at the UMass Memorial Medical Center in Worcester. He is also associate professor of surgery at the University of Massachusetts Medical School.

- The **Jonathan Mann** Award for Global Health and Human Rights, created in honor of the Harvard professor and AIDS activist who died in an air crash in 1998, has been presented to **Ruchama Marton**, MD, a psychiatrist who is the founder of Tel Aviv-based Physicians for Human Rights–Israel, and **Salah Haj Yahya**, who is a fieldwork leader for the group.

- **Calvin W. McLarin**, MD, a partner in Metropolitan Atlanta Cardiology Consultants, Atlanta, Ga, has been elected chair of the board of the Association of Black Cardiologists (ABC). **Malcolm P. Taylor**, MD, governor of the Mississippi Chapter of the American College of Cardiology, is the new president of the ABC.

- **Mark R. Lee**, MD, chief of the Section of Neurosurgery at the Medical College of Georgia, Augusta, has been named chair of the newly designated Department of Neurosurgery in the School of Medicine. **John R. Vender**, MD,

chief of the general neurosurgery service and director of the Neurosurgery/Neurology Critical Care Unit, has been named vice chair.

- **Jerome O. Klein**, MD, professor and vice chair for Academic Affairs, Department of Pediatrics, Boston Medical Center, Boston, Mass, has received the Maxwell Finland Award for Scientific Achievement, which is given for “outstanding contributions to the understanding of infectious diseases or public health.” Klein was a colleague of Finland’s for more than two decades.

- **Craig Rubin**, MD, director of the Mildred Wyatt and Ivor P. Wold Center for Geriatric Care at the University of Texas Southwestern Medical Center at Dallas, has been named first holder of the Margaret and Trammell Crow Distinguished Chair in Alzheimer’s and Geriatric Research at that institution. Also at UT Southwestern, **Thomas Südhof**, MD, director of the Center for Basic Neuroscience and holder of the Gill Distinguished Chair in Neuroscience Research and the Loyd B. Sands Distinguished Chair in Neuroscience, will lead a new center, established, by the Pauline Allen Gill Foundation, to study how brain cells communicate.

- **John Parker**, MD, a retired major general in the US Army Medical Corps, has been named senior vice president at Science Applications International Corporation (SAIC). A former commanding general of the US Army Medical Research and Materiel Command, Fort Detrick, Md, Parker will lead SAIC’s homeland defense efforts in chemical and biological defense, biosurveillance, and public health.

- **Clara A. Callahan**, MD, has been named vice dean for academic affairs at Jefferson Medical College of Thomas Jefferson University, Philadelphia. She is a clinical associate professor of pediatrics at the medical school and has served as senior associate dean for admissions and student life and Lillian H. Brent Dean for Students.

- **James Maxwell Austin, Jr**, MD, professor of clinical obstetrics and gynecology and gynecologic oncology, Department of Obstetrics and Gynecology, at the University of Alabama Medical Center, Birmingham, has been elected president of the Society of Gynecologic Oncologists.

Editor’s Note: Miscellanea Medica appears in the Medical News & Perspectives section occasionally. Items submitted for consideration should be directed to the attention of Marsha F. Goldsmith, Editor, *JAMA Medical News & Perspectives*.