

Health grant to focus on outreach to disabled kids

By LOU MANZO
SPECIAL TO THE REPORTER

Behind the podium were cutouts of young men and women dressed as astronauts, nurses, doctors, and lawyers. Each cutout held one letter and together they spelled "imagine." The Institute for Community Inclusion (ICI), in partnership with UMass-Boston and Children's Hospital Boston, is trying to do exactly that - imagine a different future for underserved children with disabilities.

At a press conference last Friday at the Roxbury YMCA, ICI officials announced that they had been awarded a \$4 million grant by the National Institute on Disability Rehabilitation and Research. The grant will go to a new initiative called "Opening Doors" within the National Center for Children and Youth with Disabilities and Special Health Care Needs.

The program has a threefold aim: First, to diagnose children with special needs at a younger age. Second, as children with special needs reach adolescence, Opening Doors will seek to place them in various recreational programs. Finally as special needs students reach their late teenage years, the initiative will help disabled young adults plan their next step. These new programs will meet needs that have not been previously addressed.

Breakthroughs in health care mean that children with disabilities are living longer than ever before. The average life expectancy 65 years ago for someone with cystic fibrosis was six months. Now it is over 32 years. In the interim, a void has been created between services and needs. Opening Doors hopes to better understand the needs of families and better connect them with pre-existing programs.

The grant will have a special focus on improving services for disabled minority children. Race and cultural background

often further complicate the process of connecting services to those in need.

"In our culture, families don't think the disabled can go to college," said Renald Raphael, program supervisor of the Haitian American Public Health Initiative (HAPHI). "Because of shame, people don't talk about it."

ICI is partnering with ten different multicultural community based organizations, including HAPHI. James Mandell, President of the Children's Hospital, stressed that community partnership would be the most important part of the grant.

"The communities will tell ICI how to implement programs," said Mandell.

ICI believes there is a need to reach out to minority populations because of Boston's changing demographics. With new immigrants moving into the city, new approaches are needed to target those segments of the population. Beyond changing demographics, State Rep Marie St. Fleur connected the benefits of Opening Doors to the recent upswing of violence in Boston.

"There are more young men in wheelchairs because of the violence. They will face emotional and development challenges. This work is timely," said St. Fleur.

This initiative may help address large issues like changing demographics, underrepresentation, and rising violence, but the program sees its mission as intensely personal. Without connecting a family to proper services, the needs of a disabled child can be a breaking point.

"Half of families break up. They have a real hard time surviving," said Elizabeth Bostic, whose six year-old son James has Cerebral Palsy. "I worry about the single mother."

Bostic is working with the ICI in hopes of "getting more families access and leveling the playing

field."

The project, though, is not solely about connecting the underserved to better programs. There is a twofold aim.

"This project is about keeping track of the results," said Ed Hayward, a spokesman for UMass. "This is the research aspect."

There are hopes to take the project farther than changing the way minority disabled youth are served in Boston

"We're hoping to design an effective way to reach the underserved," William Kiernan, the Director of ISI, said "Once we find out if it works, then these strategies can be used around the country."

Scientific achievements mean that those

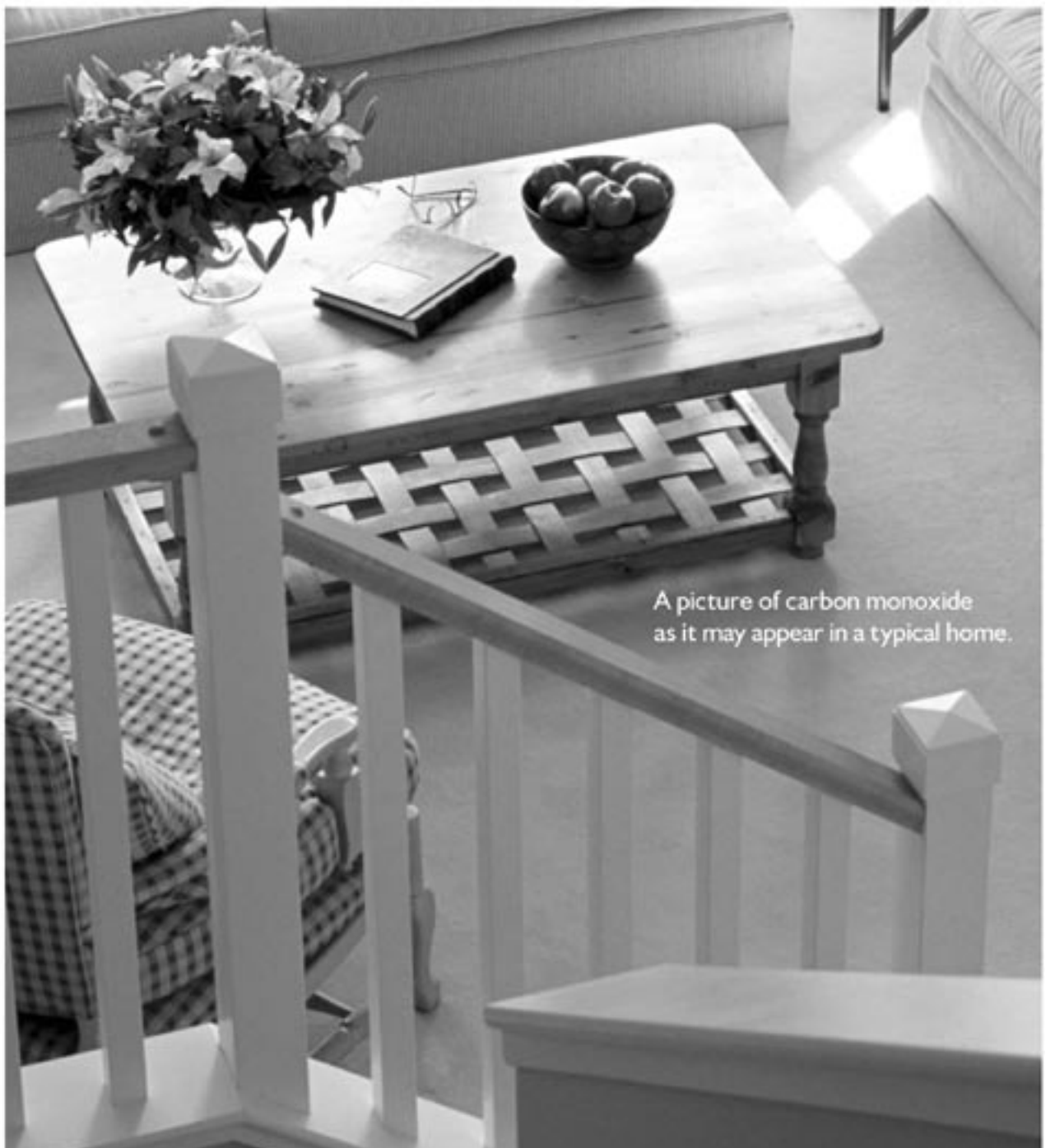


Present at the grant announcement: The Institute for Community Inclusion's Rooshey Hasnain, director William E. Kiernan, and Susan Foley; Children's Hospital Boston's Judith Palfrey, M.D., chief of the division of pediatrics, UMass-Boston Chancellor Michael F. Collins, M.D., state Rep. Marie St. Fleur, James Mandell, MD, president and CEO of Children's Hospital Boston, and Elizabeth Bostic. Photo by Harry Brett

with what were once considered terminal illnesses are living longer

lives, ICI hopes that those longer lives will be ones of fulfillment, both

for the disabled and the family.



A picture of carbon monoxide as it may appear in a typical home.

Just because you can't see it, or smell it for that matter, doesn't mean carbon monoxide isn't there. Clogged chimneys, faulty vent pipes or inadequate venting of appliances can cause an undetected buildup of carbon monoxide in your home, no matter what kind of heating fuel you use. This is especially true if you've recently installed insulation, had major renovations done or have enclosed your heating system. And that's dangerous. Carbon monoxide exposure can lead to coughing, headaches, dizziness, nausea, blurry vision and ringing in the ears. And in excessive amounts, it can be fatal.

To safeguard your home, have your chimney and heating system checked regularly. And make all necessary repairs. You can also purchase a carbon monoxide detector. Make sure it's UL- or IAS-listed, and follow the manufacturer's installation and operating instructions carefully.

If you suspect you've been exposed to carbon monoxide, get outside to fresh air, then dial 911. Then call us at 1.800.233.5325. KeySpan Energy Delivery provides emergency gas safety service, 24 hours a day, seven days a week. You can't see or smell carbon monoxide, but with KeySpan and a little careful planning, you'll always breathe easy.

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