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they have done on my behalf and for all students with special needs. And I also thank Ms. Yates. And, finally, I especially want to thank my parents for believing in me and always encouraging me to be all that I can be. I really hate to leave all my friends at Hall, but I must move on. "Thank you. Good evening."

Like Hamp, we must all move on. Great challenges lie ahead, indeed. And as you well know, they are not limited to health care reform. From the White House to your house, we must work together. We need to reassure the countless young people like Hamp across this country that they will always have health insurance, that they can have jobs and that they are an essential part of life in our communities. For surely, to be whole and part of whole communities, people deserve something to do, someone to love and something to hope for.

The leaders of the disability community are campaigning to achieve these goals and objectives. I sincerely want to thank all those leaders, including Paul Marchand and the rest of Arc's Government Relations staff, for their hard work in fighting to bring health security to every American. In addition, I commend the 100 sister organizations united in the Consortium for Citizens with Disabilities for their steadfast support. Now, we must intensify those efforts. We must each tell our personal stories so that members of Congress have before them the human faces of health care reform. We need each of you to help seize this moment of opportunity to *guarantee private insurance for all our citizens—coverage that offers choice, comprehensive benefits and freedom from unfair and exclusionary insurance practices.*

I believe that a new day has dawned for America's citizens with disabilities and for all our people. We won't always succeed and we won't always be able to do everything that we want. But with your energy and resolve, we can have health security now. And I can promise you this: we will never relent in our effort to give every person a chance to develop—fully. Because, at the end of Bill Clinton's second term, at the start of the third millennium, I want to be able to say to Hamp Rasco and Mary-Margaret Rasco and to all of America, with a clear conscience and full heart—"We did our best." And for all our children's sakes, I want each of us to be able to look at one another and say—"We did our best."



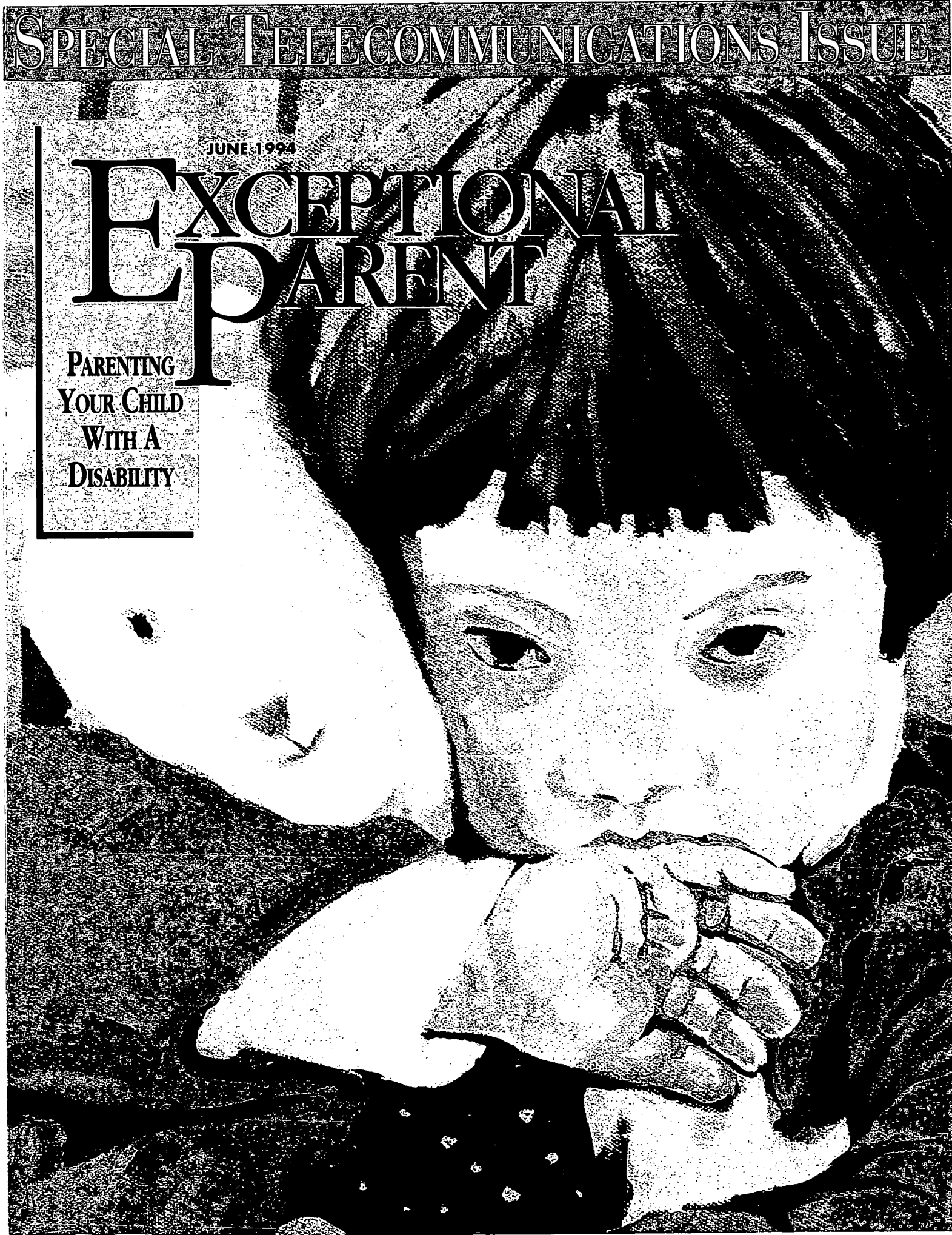
Carol H. Rasco is the Assistant to the President for Domestic Policy. In this capacity, she is President Clinton's chief domestic policy adviser, coordinating the staff of the White House Domestic Policy Council. She is the mother of Mary-Margaret Rasco and Hamp Rasco.

SPECIAL TELECOMMUNICATIONS ISSUE

JUNE 1994

EXCEPTIONAL PARENT

PARENTING
YOUR CHILD
WITH A
DISABILITY



Empowering People with Disabilities and Their Families

by Carol H. Rasco

I come to you to express my deep commitment, and that of the Administration, to the empowerment of people with disabilities.*

Those of you who work in this field—whether as volunteers, professionals or family members—boost our determination and our capacity to resolve the tremendous challenges that remain before us. Your dedication and compassion inspires us to embrace the responsibility of meeting them.

As a parent who worked exclusively in this field as a volunteer until my son was seven, and who now works as a policy-maker, I want to tell you about some of the ideas and individuals that inspire me in my daily work. Although I will focus on health care reform, our reform agenda also extends from education reform to welfare reform; from safer streets to safer transitions to adulthood for all our youth.

The White House Domestic Policy Council coordinates the efforts of the Administration, Cabinet secretaries and other federal agencies involved with the development of every aspect of our nation's domestic policy. As director of the Council's day-to-day work, I bring a strong determination that *all children shall be empowered to develop to their fullest potential*. To meet this crucial goal, our children need each of us to believe in them, and we as parents need the opportunities to nurture their growth.

As President Clinton recently stated, "Having a disability does not diminish one's right to participate in all aspects of mainstream society." On the Domestic Policy Council we take that right very seriously. Working together in public-private partnerships, we are responding to the President's call to "craft policies of inclusion, independence and empowerment that will inspire positive changes in this country and in nations around the world."

Health care reform is an indispensable part of that mission. The President's health care plan is a dramatic advance for people with disabilities and their families.

* This article is a revised and expanded version of remarks delivered by Ms. Rasco to the Arc Governmental Affairs Seminar, held in Washington, DC, on March 21, 1994. Nonprofit and disability organizations may freely make copies of this article for their members' information.

Here's why:

- It guarantees universal coverage for all Americans, and the peace of mind of having health care that is always there.
- It outlaws the current insurance practices of excluding people with pre-existing health or disability conditions, or of jacking up your rates if you get sick or become disabled.
- It forbids insurance companies from picking only the lowest-risk individuals and families, and rejecting others.

- It builds on today's private insurance system, which is primarily employer-based, while making insurance more affordable for the self-employed and subsidized for the unemployed. As a result, no one will be uninsured, even if they or members of their family experience a disability, injury or sickness.
- It offers a nationally uniform and comprehensive benefit package—in contrast to some of the other legislative proposals—that includes a range of

preventive services, doctor and hospital visits, outpatient rehabilitation, home health care, adapted durable medical equipment (including orthotic and prosthetic devices and training in their use), mental health services, and many other essential services.

Furthermore, under Senator Edward Kennedy's proposal—now in congressional committee markup—outpatient rehabilitation services would be available to those who need them to restore capacity or minimize limitations as a result of illness, injury, "disorder or other health condition." And to maintain functioning or to prevent or minimize deterioration, rehabilitation services would be provided through a four-step process—initial evaluation and periodic oversight by a qualified rehabilitation health professional; design of a maintenance or prevention program; instructions for the patient, family members or support personnel to carry out the program; and patient reevaluations.

- It provides a major expansion of long-term care coverage by adding home- and community-based services for people with severe disabilities, regardless of age or income. With a projected three million people with dis-

abilities and their families benefiting from this new program, this coverage allows people with disabilities to live in their own homes—with their families, where appropriate—and to enjoy fuller and more satisfying lives.

- It adds significant civil rights protections for the enjoyment of health care benefits, consumer involvement in the design of the new home- and community-based services for individuals with disabilities, and health care "report cards" so that families can determine the health plan that best fits their needs and reward that plan with their membership.

The disability rights movement can play a critical role in this drive for universal coverage. On May 2nd, I was delighted to be with the President as he hosted 125 leaders of the disability community in a tremendously enthusiastic rally for health care reform. As the President emphasized: "This is a battle that you may be able to lead for the rest of America... And so I ask you: Be an agent of change, an agent of empowerment. Never forget that you are carrying on your shoulders not only your cause, but ours as well. You can break through to those members of Congress. You can do it." From the White House, these leaders were joined by about a thousand others who marched across the Memorial Bridge to rally at the Lincoln Memorial; then, on to lobby on Capital Hill.

Now is the time to guarantee health security for ourselves, for our children and for the generations to come. Without secure health coverage, too many of us are not free to change jobs, move to a different location or venture from disability rolls to payrolls. Without that security, employers may be reluctant to hire a person with a disability or a person with a family member who has a disability.

These basic principles unite us. But it is our common love for our families that propels us to act.

Early in my son's life, a physical therapist who had dedicated her long career to helping young children with disabilities shared with me the words of essayist and poet Joseph Addison: "Everyone must have something to do, someone to love, something to hope for."

I am constantly reminded of those words, not only for my son, Hamp, but for all the people with whom I've worked. In our quest to empower people, we must strive to fulfill these ends at each stage in life. In this process, we have myriad questions to ask and actions to take.

What do persons with disabilities have to do? For a young child, is a preschool program or other early intervention available? For a school-age child, is school relevant, safe and effective? Are our schools and transitional programs teaching both how to make a living and how to live? And, for adults, is there a job, day activity or voluntary service that satisfies and excites? As President Clinton said in Memphis last November: "I do not believe we can repair the basic fabric of society until people who are willing to work have work.

Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children... We cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives." Those powerful thoughts are particularly apt for our citizens with disabilities who, too often, experience high rates of unemployment and underemployment.

What do persons with disabilities have to hope for? And what do we who love them have to hope for? Linda Charlton, the mother of a two-year-old daughter with Down syndrome, recently described her goals for her Katie before a superb and productive meeting of the President's Committee on Mental Retardation:

"First, we want her to feel loved... to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school. There's even a part of us that hopes she'll continue her education after that... I wonder if she'll ever get married... if she doesn't, I hope at least she has a companion to enjoy life with. And if we could, we'd like to see her remain as happy as she is today... Our Katie—who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths and the color red."

These are dreams and feelings to which any parent can relate. Many of them were fulfilled for me when my son was asked last year by the members of his high school graduating class to give one of the commencement addresses. I will never forget that moment, nor will Hamp. Here was the young man whom we were once told would not survive or if he passed the hurdle of his first days, would have to be institutionalized. But Hamp defied those predictions, living at home and attending school with his non-disabled peers. This is the speech that he wrote, on his own, politely declining his mother's offer of help. Hamp said that this was his speech to give:

"Hello, my name is Hamp Rasco. I am pleased to share with you what attending Hall High has meant to me.

"I enjoyed the pep assemblies and the band. I enjoyed talking with friends in the cafeteria and going out into the community with my CBI class.

"After graduation I plan to find a job in the community where my social skills can be put to use. This is important to me because I want to make new friends with all kinds of people.

"I would like to encourage other students with special needs to never give up, work hard to do a good job and be proud and happy about what you do at school.

"I want to thank Dr. Anderson and the vice principals for their support of my program. I want to tell Ms. Chapman and Mr. Smith how much I appreciate all the work



Carol Rasco and son Hamp celebrate his 20th birthday. (Photo: Charles Archambault/Archambault Photography)

THE WHITE HOUSE
WASHINGTON

Carol Hampton Rasco

Assistant to the President for Domestic Policy

Carol Hampton Rasco serves as President Clinton's top domestic policy advisor at the White House.

In this role, Carol directs the President's Domestic Policy Council, which consists of Cabinet Secretaries and heads of domestic agencies, and is responsible for helping to shape, implement and articulate the President's domestic policy agenda. In addition, Carol monitors the legislative process and implementation of initiatives.

Carol is from Arkansas and worked as President's Clinton's chief policy advisor in the Arkansas Governor's office for ten years, serving as his Senior Executive Assistant. From 1985 through 1992, she was Governor Clinton's liaison to the National Governors' Association, while he served as chairman as well as lead Governor on welfare reform, child care and health care reform.

Carol received a bachelor's degree from the University of Arkansas and earned a master's from the University of Central Arkansas. She has taught in the public school system and worked as a middle school counselor.

Prior to joining Governor Clinton's staff in 1983, Carol worked extensively as a volunteer in Arkansas with arts organizations, disability advocacy groups and the United Methodist Church.

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Asst. to the President for Domestic Policy

Old Executive Ofc. Bldg. Rm. #213

White House

Washington, DC 20502

Dear Ms. Fleming,

This letter is written to inform you about the development of a much needed affordable housing project located in Houston, Texas. Our organization, The Loving Arms Foundation in partnership with the H.E.L.P. Organization propose to develop a 50 unit residential facility that will house at least 50 families with adult family members and or children who have AIDS or tested positive for the HIV virus. This new construction project will provide permanent supportive housing to homeless families of low and moderate incomes.

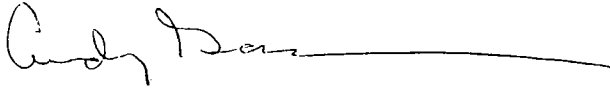
I have attached for your review a copy of an application for HUD's Supportive Housing Program which will fund three years of operating and support service expense. I have also attached a Project Summary for your review at a glance. This application will give you more insight as to the specifics of this project including the types of services that will be available at this site and further enlightenment on what the two sponsors are about.

The need for this type of supportive housing is overwhelming for this area. Houston currently ranks fourth in the United States in the number of persons infected with HIV/AIDS. What's more, women and children are the fastest growing segment of this population. As you know, with the assistance of a Ryan White Award Grant, the Loving Arms Foundation is currently operating an HIV/AIDS Pediatric Day Care Center in Houston that provides free support services to 72 children from 55 families over the course of a year.

The H.E.L.P. Organization is the nation's largest developer and operator of supportive family housing. Based in New York City, H.E.L.P. Organization is the nation's largest developer and operator of supportive family housing. Based in New York City, H.E.L.P. provides housing and support services to over 2,000 families in over 1,250 housing units build and managed by H.E.L.P. H.E.L.P.'s housing facilities have earned its praise and recognition by the U.S. Congress as a National Demonstration Program.

Please feel free to call if you have any questions or want more information about this worthwhile project for the City of Houston. I look forward to your support of this project.

Very Truly Yours,

A handwritten signature in black ink, appearing to read "Audrey Gassama", followed by a long horizontal line extending to the right.

Audrey Gassama
Executive Director

cc: Karen L. Krautheim, H.E.L.P. Organization

Attachments