OF EQUALITY

Building

a community

for

everyone

THE MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL

Communities are rich and diverse. They exist through a web of informal relationships that collectively offer strength and protection. People in communities

share life's many opportunities and contribute to life's experiences.

We believe in a community that welcomes everyone, no matter how complex or challenging their disability. The individuals whose stories grace the following pages are bringing that vision of equality to life.

All People are Entitled to the Freedom of Community Living

All people with disabilities can live in their communities with appropriate support for their safety and well-being. The Americans with Disabilities Act (ADA) recognizes segregation and isolation as the greatest forms of discrimination against people with disabilities. Laws like the ADA open community services, programs and activities to everyone, regardless of the severity of their disability.

In reality, however, the cost of running institutions is so prohibitive that people with disabilities living in homes in the community who need support services are not receiving them. Meanwhile, several million dollars in additional State funds could be realized by the year 2000 if people now in institutions were moved to the community and were provided with full supports.

When Susan Kierson first laid eyes on eight-year-old Terry Shiau in the Great Oaks Center, she didn't see a child with cerebral palsy and a seizure disorder...or a child who required intensive medical care to stay alive.

Susan looked at Terry and saw a child. And just like that, she fell in love.

An advocate from the Supported Employment Enterprise Corporation helped convince the State that Terry's needs could be met in Susan's home; the University of Maryland Community Capacity Team helped Susan figure out how. Soon thereafter, the court made Susan Terry's legal companion. Terry made her a mother.

With the help of a home health nurse, Susan easily learned to tube-feed Terry, give nebulizer treatments and do postural drainage and chest percussions. Susan explains, "I can take care of improving Terry's health and make her part of my family, too."

And how Terry's life has improved. At Great Oaks, Terry was barely able to move. Six months later, at home in Walkersville, Maryland, she straightens out her body, moves from side to side, holds up her head and focuses on people and objects. She has even begun to smile and laugh and express what she wants.

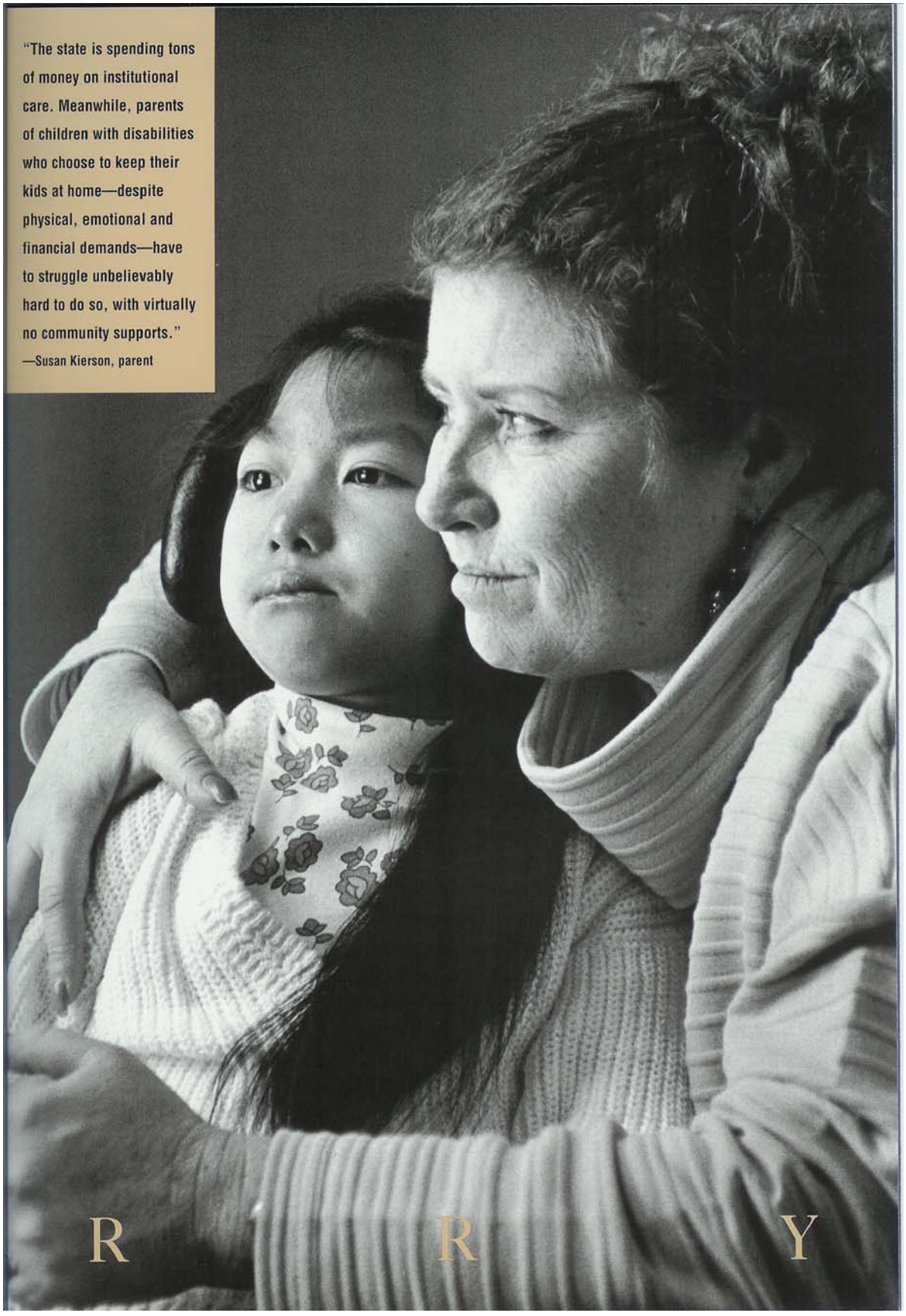
At school, an aide helps Terry participate with her third-grade class. "After school, Terry enjoys music and Barney and the feel of air on her face when we take walks," says Susan, "but most of all, she loves being with people, especially her cousins."

When questions arise, Susan turns to Terry's doctor for advice. Just as frequently, though, she'll consult other parents of children with disabilities who, she says, provide a wealth of information and support.

"They understand that I am parenting Terry completely by choice; that raising her is a privilege, not a dilemma. They know that every day, I receive at least as much as I give.

"I am rewarded just by being with Terry...by seeing her smile at me or call for me. She touches all the same things in me that my biological child touches."

T E


"The state is spending tons of money on institutional care. Meanwhile, parents of children with disabilities who choose to keep their kids at home—despite physical, emotional and financial demands—have to struggle unbelievably hard to do so, with virtually no community supports."
—Susan Kierson, parent
R
R
Y

People with Disabilities are Individuals; Stereotypes Impede Their Progress

Traditionally, people with disabilities either have been underemployed or offered work in traditional jobs like cleaning or food services. Grouping people together as if they have the same needs and choices ignores their uniqueness. The supports they need to be included in their communities vary from person to person; paying for services that don't fit real needs is unwise...and wasteful.

Given the opportunity to hold satisfying jobs in the community, people with disabilities make millions of dollars in tax contributions to state and federal governments and support local economies through the purchase of goods, services and housing.

Since Jeffrey Carroll came to work as a data entry clerk at the Food and Drug Administration's Center for Veterinary Medicine, productivity is up. So is morale.

Ably working 15 data bases on four computers, he is the picture of diligence, says his supervisor, Patsy Gardner. "Jeffrey is very focused. When he has a big project, he doesn't complain, he just rises to the challenge and chips away at it until he's done."

Another supervisor, Frances Benedict, concurs. "Jeffrey inspires all of us. One of my co-workers says that seeing Jeffrey work so hard makes him work harder, too. And he's so punctual that everyone else feels guilty if they're late."

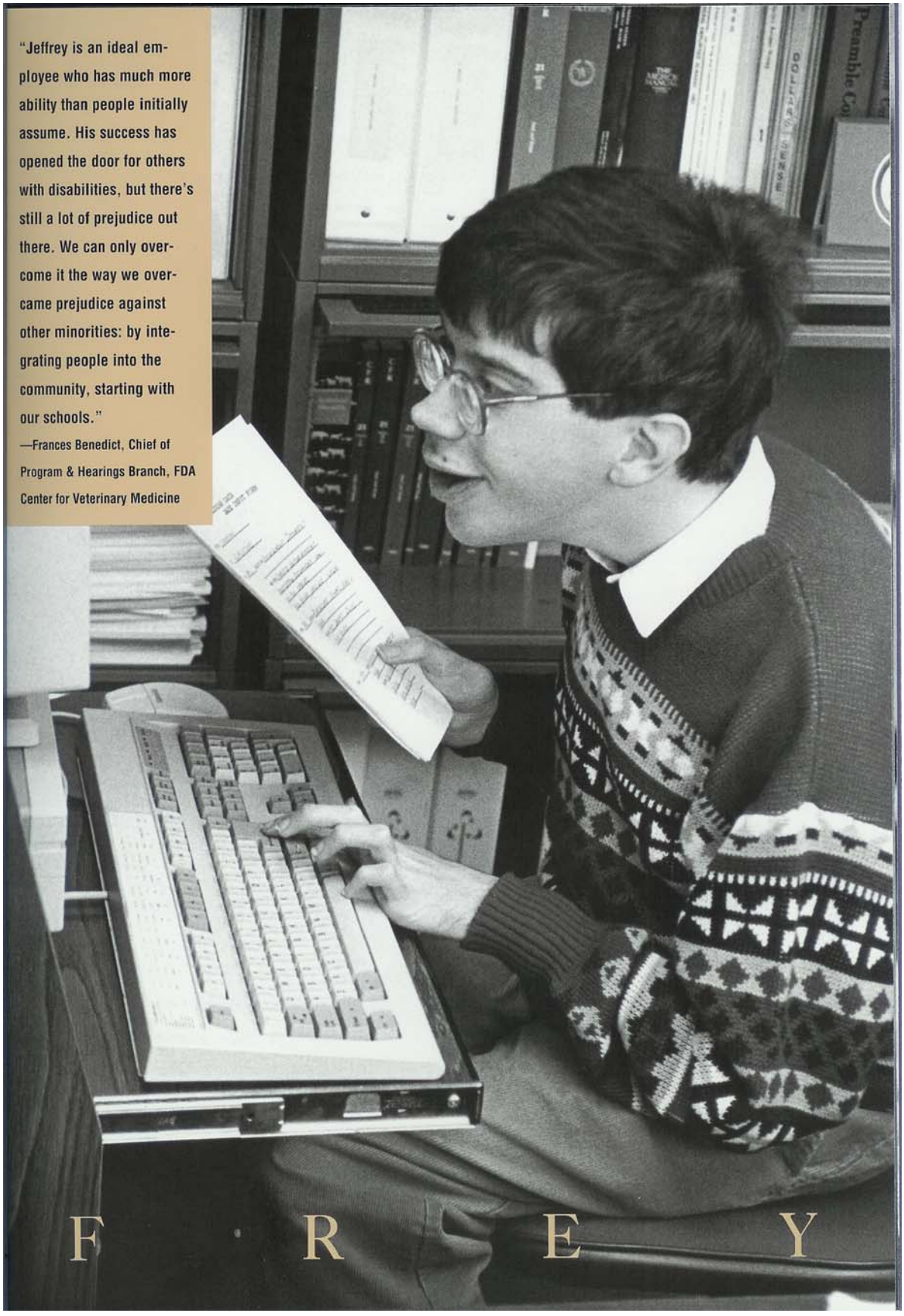
Jeffrey, who has mental retardation, started working at FDA in 1991, through an internship arranged by a community organization called TransCen. SEEC, the Supported Employment Enterprise Corporation, devised a guide from which Jeffrey could work and taught him to travel independently to and from work, despite his being legally blind.

By the end of the internship, Jeffrey had proven himself and was hired as a temporary employee with benefits. His supervisor says he's so invaluable to the office that she's determined to have him made a permanent employee.

It wasn't all smooth sailing. In the beginning, not everyone was comfortable about Jeffrey's presence, but his engaging personality, his vast knowledge of movie trivia and his obvious abilities soon turned fellow employees into fans. Today, he's fully integrated in all office activities, and the person initially most resistant to his hiring is the one who misses him most when he's on vacation.

Jeffrey's success has exceeded even his mother's expectations. "I didn't have high hopes because the success stories I heard about always involved people who seemed less disabled somehow," she explains. "But this job has been marvelous for his independence and his self-esteem. To be included and accepted into a work situation is just wonderful for him."

J E F



"Jeffrey is an ideal employee who has much more ability than people initially assume. His success has opened the door for others with disabilities, but there's still a lot of prejudice out there. We can only overcome it the way we overcame prejudice against other minorities: by integrating people into the community, starting with our schools."

—Frances Benedict, Chief of Program & Hearings Branch, FDA Center for Veterinary Medicine

Families are the Greatest Resource Available to Their Children

Families want to be seen as a 'family' rather than a 'family with a child with a disability'. They want to use the same services and supports their friends and neighbors use while still having their unique needs met.

Maryland's Developmental Disabilities Law states that "it is the policy of this state to enhance the quality of life for children with developmental disability and their families, to preserve family unity, and to promote family stability..." Agencies providing support to families are doing terrific things by allowing families to decide what it is they need and then providing it. Unfortunately, they report a much greater need for their services than they are currently funded to provide.

When Carissa was born Ruth and James Coates took their cues from her. "We let her show us what she could do," says Ruth, "and she really believes she can do anything!"

Carissa is a busy two-and-a-half year old girl. Her life is filled with nursery school and church, football games and playing with friends and family. She is happy, bright and persistent—pushing on until she accomplishes what she is after.

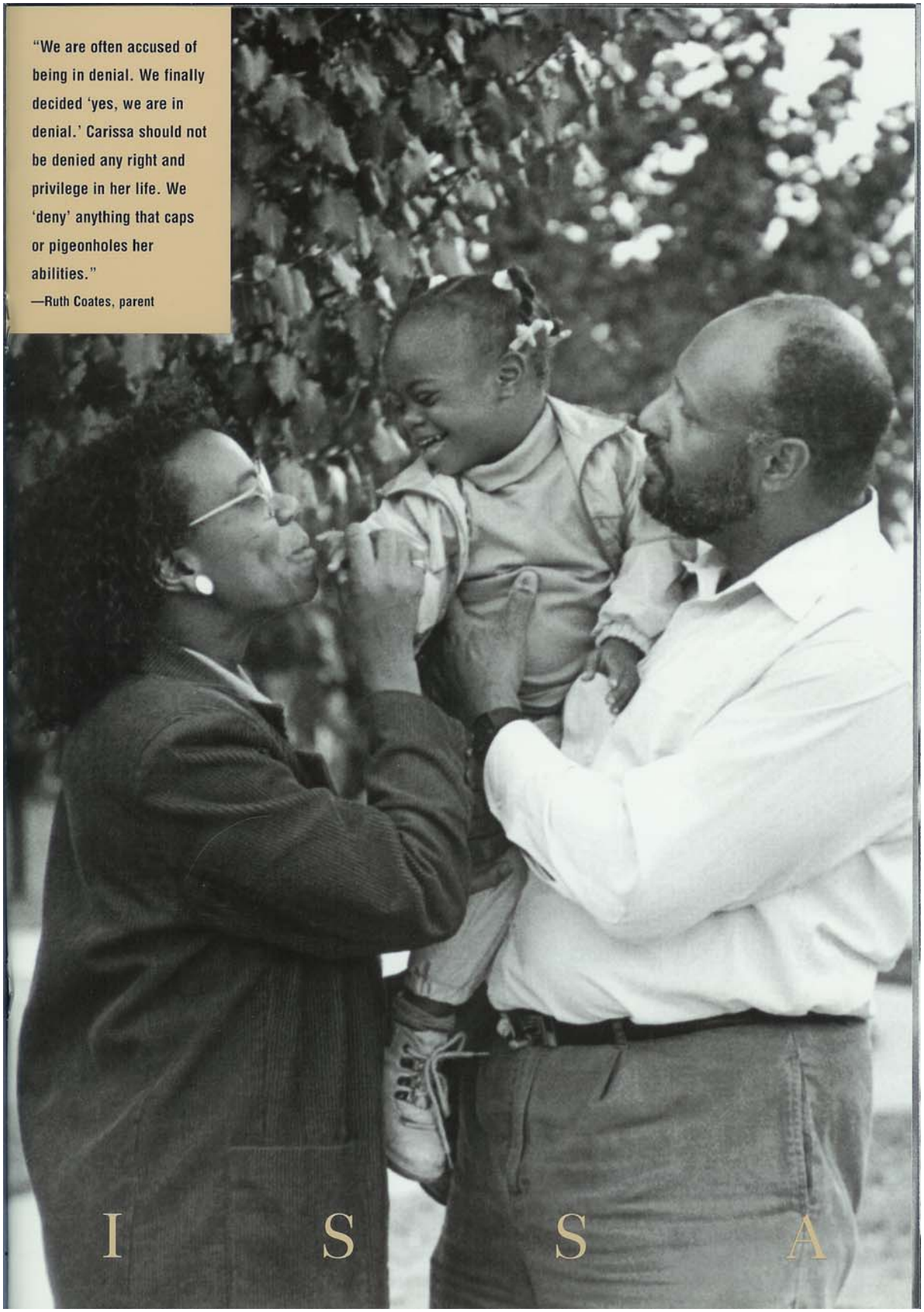
Preconceived opinions or outdated perceptions are not allowed to play a role in Carissa's life. The Coates, Ruth and James, Carla, James and John, believe that the challenge is not Carissa's but theirs and the systems' to find the best way to support and enable their daughter and sister.

And they have all risen to the challenge. The Coates believe strongly in a family vision that embraces each members' individuality. To ensure that her opportunities to a full, happy life are not compromised, Carissa and her family kindled a sense of team work with the public school, the day care provider and Carissa's various therapists. The team members correspond weekly, sharing notes, thoughts and anecdotes about Carissa. Their fundamental goal is to provide Carissa with what she needs to grow, learn and play to the best of her ability.

The Coates family moved away from wanting a 'pressure cooker' of therapies and things to fix her to 'enabling' her and providing her an environment where she can flourish. The most effective early intervention specialists have combined their wealth of knowledge and skill with Carissa's abilities and the family's enthusiasm. For example, Carissa's brothers, James and John, take part with her in physical therapy. Carissa and her mom make shopping a game—matching colors and numbers.

Ruth knows that self-confidence and a positive outlook are crucial to Carissa's future happiness and independence. She believes that these qualities are nurtured only in typical places such as preschool, church and Carissa's neighborhood. Artificial places that congregate children with disabilities are unacceptable in that they keep them from taking part in everyday life. As Ruth says, "The environment we put people into and the environment we put into people MATTERS."

C A R


"We are often accused of being in denial. We finally decided 'yes, we are in denial.' Carissa should not be denied any right and privilege in her life. We 'deny' anything that caps or pigeonholes her abilities."
—Ruth Coates, parent
I S S A

Home Ownership Can Become a Reality

Choosing a home is a right that people with disabilities seldom have the opportunity to exercise. Those who would like to rent or own a home typically lack the resources to do so. Others are excluded from the community because of the complex nature of their disabilities.

The Maryland Developmental Disabilities Council advocates for and promotes opportunities for people with developmental disabilities to own or rent their own homes. Through the provision of technical assistance and collaboration with other organizations the Council supports the right of people with disabilities to live their lives on their own terms... choosing where and with whom they live.

When Richard Lowry tells you that people don't belong in institutions, he speaks from experience. Richard spent 20 years in the Rosewood Center, and even now—a decade after leaving—he cannot talk about the experience.

If you want to talk about owning a home, however, Richard will happily oblige. Last April, he and his friend, Dennis Anderson, purchased a beautiful, two-bedroom condominium in the Running Brook section of Columbia—and made their dream come true.

Richard and Dennis had been roommates in a house operated by an organization called Community Choice. Both men wanted to buy a home, but knew they could afford to do so only by pooling their incomes. Community Choice helped them find a real estate agent and legal assistance to put their plan in motion.

Richard and Dennis chose their condo because of its proximity to the mall. Immaculately kept, it's decorated with furniture from Dennis's family, posters, paintings and lots of plants.

Each week, a counselor stops by to help Richard and Dennis bank and shop. She also drives Richard to doctor appointments. Otherwise, the pair are self-sufficient, sharing chores like cooking, laundry and cleaning.

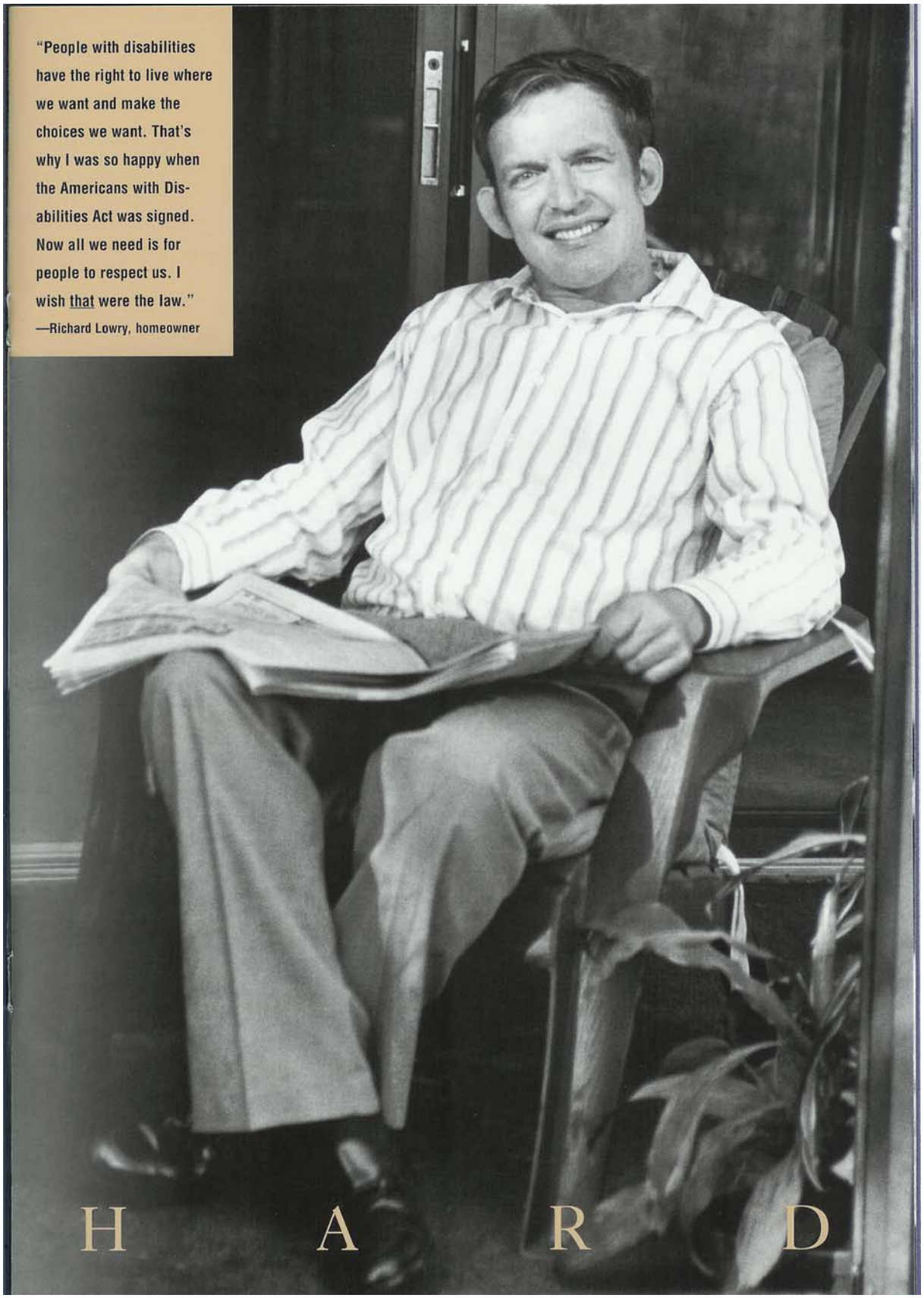
To relax, Richard and Dennis go bowling, go to dances, or just enjoy their garden. Richard, a movie buff, collects videos and is a big band music fan.

He is also starting a self-advocacy group for people with disabilities in Howard County. The group's goal is to improve transportation, recreation and housing opportunities.

"I hope more people like me and Dennis will buy their own place. It makes better financial sense and it's cheaper than renting," he explains.

"Besides," he continues, "I used to be locked up a lot and that's no life. I have freedom now. Everybody should."

R I C


"People with disabilities have the right to live where we want and make the choices we want. That's why I was so happy when the Americans with Disabilities Act was signed. Now all we need is for people to respect us. I wish that were the law."
—Richard Lowry, homeowner
H A R D

Inclusion is a Right, Not a Privilege

Children with disabilities have the right to be educated in the same schools and classes as their siblings and their neighbors. When children are put in "special programs" and are excluded from regular schools, recreation, community services and community life, their families are excluded, too.

Organizations like the Maryland Coalition for Inclusive Education work to ensure that students with disabilities get the individualized education programs and supports they need to participate fully, with non-disabled peers, in school, home, work and community life. Growing up side-by-side prepares all children—disabled and non-disabled—to share the adult world.

Like a lot of eight-year-old girls, Catherine Uppole loves Barbie dolls, the color pink and watching "Full House." In fact, what's most striking about Catherine is not that she has Down Syndrome, but that green vegetables are her favorite food...and that she absolutely adores going to school.

The Montgomery County second-grader beams as she talks about the alphabet, counting or what she did in gym. If only she didn't have to learn to write lower case letters, Catherine is sure school would be perfect. Especially the part about being in a regular classroom.

"Even as young as she is, Catherine can feel the difference," says Catherine's mom, Melinda. "I don't want her to feel like she's not 'normal,' or that she can't be included. She can learn like anyone else."

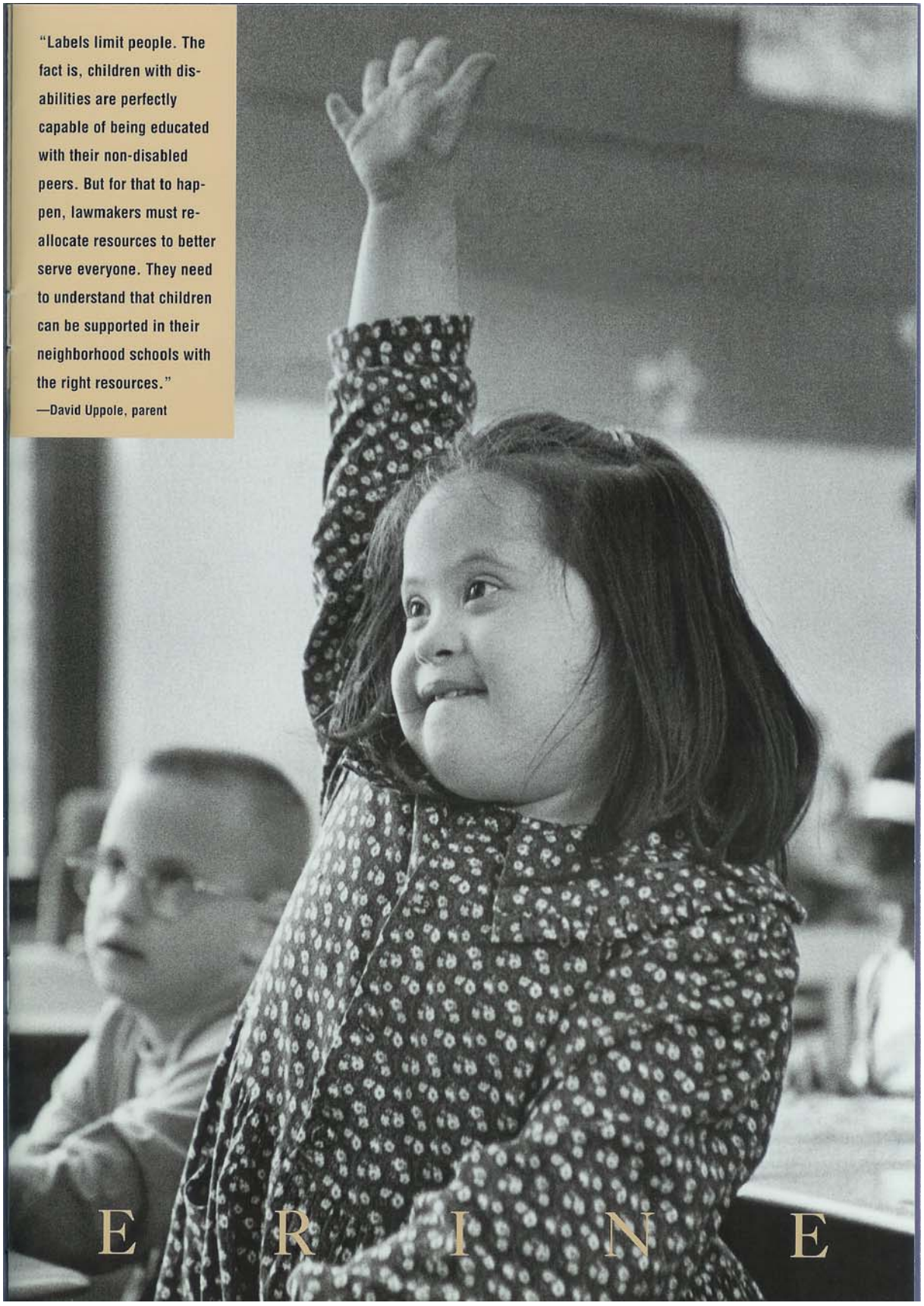
To make this happen, Catherine's parents, teachers, and therapists worked with the Maryland Coalition for Inclusive Education to develop an individualized education program for Catherine. It calls for weekly sessions of speech and occupational therapy, plus an aide to support her classroom work. Catherine's dad, David, feels the program gives Catherine something to reach for. "The more you expect from someone, the more they can achieve," he says.

And without a doubt Catherine is achieving. She's learning to read. She's developing friendships. And her vocabulary is growing every day, something that never happened when Catherine was grouped with other children who had language disabilities.

"It was always our hope that Catherine would have friends in the neighborhood, and that she'd feel part of our community. Being in a regular classroom has made that possible," David says.

The reason, he believes, is simple. "If we teach kids early that people with disabilities are people first—if we show them there's no need for fear or discrimination—then they can accept differences in others more easily. And everyone wins."

C A T H


"Labels limit people. The fact is, children with disabilities are perfectly capable of being educated with their non-disabled peers. But for that to happen, lawmakers must reallocate resources to better serve everyone. They need to understand that children can be supported in their neighborhood schools with the right resources."
—David Uppole, parent
E R I N E

A MESSAGE TO ELECTED OFFICIALS

Given appropriate supports, all people with disabilities can take part fully in community life. The success stories on the preceding pages illustrate the possibilities.

Right now, waiting lists are overflowing with individuals whose dreams are to have similar opportunities. They are counting on you to promote initiatives, laws and funding appropriations that recognize that:

PEOPLE WITH DISABILITIES ARE INDIVIDUALS. *Their specific needs, choices and desires deserve the respect and support given to all citizens. It's a wise policy to foster services and supports adapted to actual needs rather than a less effective "one-size-fits-all" approach.*

SEPARATE IS NOT EQUAL. *No law requires public funding of institutions or separate schools for those with disabilities. By contrast, laws like the ADA open public services, programs and activities to everyone, regardless of the nature or severity of their disability. The administrative ease of congregated, segregated services is not an acceptable reason for cutting people off from natural ties to their family, friends, co-workers, neighbors, peers and community.*

IT'S TIME TO CLOSE THE SPENDING GAP BETWEEN HEAVILY FINANCED PUBLIC SERVICES FOR SOME AND LITTLE OR NO HELP FOR OTHERS. *Lawmakers must safeguard the enormous public investment in services for people with developmental disabilities and make sure it is distributed fairly. Most children with severe disabilities are cared for by their families. Many have needs beyond their family resources but receive little or no publicly funded support. The fact is their special needs often are no different than those people now living in costly public institutions. Almost all could be supported successfully in homes in the community with sufficient resources. If people in institutions were served in the community, a large savings could be reallocated to support families providing care at home and to serve more people on the waiting list for community services.*

ALL PEOPLE WITH DEVELOPMENTAL DISABILITIES HAVE EQUALITY UNDER THE LAW. YOUR VISION AND LEADERSHIP ARE VITAL IF PEOPLE ARE TO HAVE EQUALITY IN THEIR EVERYDAY LIVES.

The Maryland Developmental

Disabilities Council advocates

for public policy and

supportive practices and

opportunities that promote

the full inclusion of all people

with developmental

disabilities in community life.

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